



NCRI

National
Cancer
Research
Institute

NCRI Psychosocial Oncology & Survivorship Clinical Studies Group

Annual Report 2015-16



Partners in cancer research

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NCRI Psychosocial Oncology & Survivorship CSG Annual Report 2015-16

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

Over the past 12 months, the Psychosocial Oncology & Survivorship (POS) CSG has made substantial progress towards achieving the strategic objectives we set in 2014. We successfully completed our five year review and look forward taking our work forward over the next five years. We continue to collaborate with site specific CSGs. Thus, CSG members have been invited: to join the Supportive Care, Transfusion & Late Effects Working Party (led by the Haematological Oncology CSG) and attend the recent strategy day for the Lymphoma CSG. We aim to develop further collaborative research studies with colleagues from the other CSGs in the coming year. The CSG and Subgroups have worked hard to initiate and develop their research ideas and this has culminated in the submission of 22 grant applications to both Government and charity funders: of these six were successful. Three grant applications were collaborations with other CSGs (Brain, Bladder and Supportive & Palliative Care).

A key challenge for the CSG is the lack of specific funding streams for psychosocial oncology and survivorship research. However, we will continue to explore with individual funders whether funding opportunities exist for this type of research. In addition, agreeing the payment of NHS excess treatment costs under AcoRD continues to be a substantial challenge for non-pharmacological/behavioural intervention studies, such as those that are typically undertaken in the field of psychosocial oncology and survivorship research. Finally mechanisms for research support differ in the devolved nations. This has meant that some studies have not been conducted outside England.

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 CSG differs from site-specific CSGs in that most members are employed in the university sector rather than the NHS. We appointed Dr Sarah Slater and Dr Chris Barton as trainees to the CSG, and over the past year they have contributed to the Understanding and Measuring Consequences of Cancer and its Treatment and Lifestyle and Behavioural Change Subgroups.

In the last year, Mr Matthew Nankivell joined the POS CSG. Dr Gill Hubbard rotated off the CSG having contributed significantly to the CSG through her leadership of the Lifestyle & Behavioural

Change Subgroup. Dr Lynn Calman returned from maternity leave – thanks go to Dr Rachel Taylor who led the Understanding and Measuring Consequences of Cancer and its Treatment Subgroup in her absence.

3. CSG & Subgroup strategies

Main CSG

Aim: 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. We aim to expand the breadth of the portfolio over the next three-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 that 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 capture.
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.

Achievements:

In past 12 months the CSG has

- Successfully completed our five year Progress Review.
- 18 grant applications submitted of which six were successful. Three grant applications were collaborations with other CSGs (Brain, Bladder and Supportive & Palliative Care).
- We continue to collaborate with site specific CSGs; CSG members have been invited: to join the Supportive Care, Transfusion & Late Effects Working Party (led by Haem Onc CSG) and attended the Lymphoma CSG strategy day in October.
- We co-hosted a sub-speciality meeting with the Supportive & Palliative Care CSG on 17 June 2016.

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

Aim: Develop and conduct research to understand the experiences of people living with cancer, to identify the consequences of living with and beyond cancer, including psychosocial and/or physical consequences of treatment, whether shortly after treatment or in the longer term.

Achievements:

1. EPiC: Evaluation of Patient-reported outcome protocol content and reporting in UK cancer clinical trials: a mixed-methods study (Dr Kyte & Subgroup members) funded by

Macmillan Cancer Research. This study commenced in January 2016 and the first paper submitted to BMJ in May 2016.

2. We have started to work more closely with other CSGs, e.g. Dr Lynn Calman has submitted a grant with members of the Lung CSG, Dr Rachel Taylor attended the TYA CSG strategy day, we were approached by the Lymphoma CSG about a potential project.
3. Submitted a number of 'Subgroup involved' grant applications, e.g. RCLCF, Macmillan, Sarcoma UK.

Interventions to improve outcomes in people affected by cancer Subgroup (Chair, Professor Mary Wells)

Aim: To improve the experiences and outcomes of those affected by cancer (patients, family members and carers) by developing and facilitating research that addresses the psychosocial and supportive care needs of these populations, including interventional research that develops individualised models of care and tests different modes of delivery. In the next 12 months the following will be prioritised as topics for future research:

- Developing an intervention for fear of cancer recurrence.
- Unmet needs in haematological cancer patients.
- Psychosocial consequences of HPV cancers.

Achievements:

1. Submitted eight Subgroup involved grant applications to develop and evaluate interventions, e.g. Breast Cancer Now study of a community pharmacy led intervention to support women on endocrine therapy for breast cancer.
2. Developed productive collaborations with other CSGs and working groups, e.g. Sarcoma CSG (one successful grant application, invited talk at British Sarcoma Group, invitation to strategy day) and Haematology working group.
3. Initiated sub-group led project ideas on financial burden of cancer and fear of recurrence.

Lifestyle and behavioural change Subgroup (Chair, Dr Gill Hubbard)

Aim: To develop and run research projects about health behaviours and in particular, to examine if lifestyle change aids recovery and improve chances of survival.

Achievements:

1. The Subgroup is on target for conducting two CSG-led large-scale multi-centre clinical trials:
 - A CSG-led study (EFFECT) funded by *Breast Cancer Now* has been completed by the team. The study tested the feasibility of a face to face physical activity (PA) programme for people with breast cancer after surgery. The team were successful in obtaining further funding from the Chief Scientist Office (Scotland) to develop the PA programme further by incorporating a telephone-delivered PA programme. The team therefore will have conducted all necessary preliminary work to then submit a protocol for a full multi-centre effectiveness trial of a PA programme where people with breast cancer will be given a choice of face to face or telephone delivered PA programmes.
 - The CSG has recently collaborated on a study about lifestyle, quality of life and stomas. A survey of people living with a stoma has been conducted and the team plan to conduct further preliminary work about PA and stomas. This preliminary work is being planned in advance of the development of a large multi-centre effectiveness trial of a PA programme for people with stomas.

2. The Subgroup continues to conduct high quality PPI:
 - Elspeth Banks, who is a member of the NCRI Consumer Forum, is a co-applicant on the EFFECT trial and continues to play a leading role in the CSG.
 - The stoma research includes the involvement of patient advisors from Bowel and Cancer Research.
3. The Subgroup continues to collaborate with other CSGs:
 - The EFFECT trial is supported by the Breast CSG.
 - The stoma work includes members from the colorectal CSG.

4. Task groups/Working parties

None have been convened by the POS CSG.

5. Patient recruitment summary for last 5 years

In the Psychosocial Oncology & Survivorship CSG portfolio in 2015-2016, 18 trials closed to recruitment and 14 opened. The number of people recruited to Psychosocial Oncology & Survivorship CSG portfolio studies increased in 2015-2016. The number recruited to interventional studies was maintained at a similar level to the previous year; however, recruitment figures are highly influenced by the availability of clinical trials.

Table 1 Summary of patient recruitment by RCT/Non-RCT

Year	All subjects		Cancer patients only		% of cancer patients relative to incidence	
	Non-RCT	RCT	Non-RCT	RCT	Non-RCT	RCT
2011/2012	3579	80	3497	80	-	-

Table 2 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	2803	383	2461	368	-	-

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

Links between the POS CSG and other groups are detailed below:

- Professor Watson is a member of Primary Care CSG.
- Professor Wells is a member of the Head & Neck CSG Survivorship Subgroup.
- Dr Taylor is a member of the TYA Health Services Research Subgroup.
- Dr Armes and Ms Morris are members of the Symptom Management Subgroup convened by the Breast CSG.

- Dr Peter Hall is a member of the Screening, Prevention & Early Diagnosis (SPED) Advisory Group.
- Dr Armes & Professor Watson are members of Supportive, Transfusion and Late Effects Working Party initiated by Haematology Oncology CSG.
- Dr Calman is a member of Lung CSG.

International Links:

- Professor Hulbert-Williams chairs The Research Committee of The International Psychosocial Oncology Society (IPOS).
- Professor Wells is Co-Chair of Research Working Party of the European Oncology Nursing Society (EONS).
- Professor Wells & Dr Jo Armes are members of Expert Reference Group for JBI CONnECT+ Cancer Care Node.

7. Funding applications in last year

For submissions for 2015-2016 for studies that have been developed by, or alongside, the CSG the overall success rate was 27%. Whilst we are satisfied with the submissions we have made and believe they contribute meaningfully to the portfolio, not all our submissions were successful. The funding opportunities for this type of research are more limited than for disease-specific clinical or biomedical 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 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 portfolio.

Table 3 Funding submissions in the reporting year

Other committees			
Study	Committee & application type	CI	Outcome
EPiC: Evaluation of Patient-reported outcome protocol content and reporting in UK cancer clinical trials: a mixed-methods study	Macmillan Cancer Support	M Calvert & D Kyte & PROMS Subgroup	Successful
RECORD: Recording oncology consultations for patient benefit: identifying and addressing ethical and legal concerns	NIHR Programme Development Grant	K Beaver	Unsuccessful
Opening the door to communication about sexual wellbeing after treatment for gynaecological cancer	Wellbeing of Women	K Beaver co applicant	Unsuccessful
Quality of Life After Bladder Cancer (Q-ABC): a comparison of patient related outcomes following radical surgery and radiotherapy	NIHR RfPB South Coast, project grant	A Nikapota, J Armes & P Hall	Unsuccessful
Examining the feasibility of a pharmacy intervention to increase adherence to adjuvant endocrine therapy (AET) in women diagnosed with breast	NIHR HS&DR, programme grant	C McCowan, E Watson, M Wells. E Banks co-applicant	Unsuccessful
Information needs in melanoma patients	NIHR RfPB North West, project grant	K Beaver	Unsuccessful
Improving adherence to exercise in palliative care	Dunhill Medical	J Reid	Pending

	Trust, Fellowship application		
CLASP Programme: Life Affirming Survivorship support in Primary care	National Institute for Health Research Programme Grant	P Little and L Yardley E Watson and C Foster are co-applicants	Successful
Macmillan HORIZONS programme	Macmillan Cancer Support - 5 year continuation programme grant	C Foster L Calman co-applicant	Successful
CRIB II	NIHR - HS&DR	G Hubbard, M Wells, N Hulbert-Williams	Unsuccessful
Fatigue Review and Management in Glioma (FRaMinG): a twin-centre feasibility study examining tailored, non-pharmacological interventions for fatigue.	Brain Tumour Action	R Rooney M Wells	Pending
Raising awareness of skin cancer in schools	Melanoma Focus	G Hubbard E Banks was co-applicant	Unsuccessful
Improving adherence to adjuvant endocrine therapy in women with breast cancer: a feasibility trial of a community pharmacy intervention	Breast Cancer Now	E Watson M Wells & E Banks are co-applicants	Unsuccessful
Symptom appraisal following treatment for primary breast cancer, and pathways to diagnosis of a recurrence or new primary cancer	Breast Cancer Now	E Watson N Hulbert-Williams is co-applicant	Pending
Life After Prostate Cancer Diagnosis (LAP-CD)	Prostate Cancer UK / Movember	A Glaser / A Gavin E Watson co-applicant	Successful
Evaluating supported SELF-management in Stage I endometrial cancer: a multi-centre randomised controlled trial (SELFIE)	HTA	K Beaver	Unsuccessful
How do the new NICE guidelines influence GPs' decisions about direct access diagnostic and two week referral? A CSG wide significant events audit.	CRUK	K Beaver co-applicant	Unsuccessful
Acceptability and deliverability of a telephone intervention (Mini-AFTER) for the management of fear of recurrence in breast cancer survivors	Breast Cancer Now	S Cruickshank J Armes co-applicant	Successful
Cancer Recovery in Morecambe Bay (Lancashire & Cumbria)	Health Foundation	K Beaver co-applicant	Unsuccessful
Novel approaches to understanding and treating fear of recurrence in breast cancer survivors	Breast Cancer Now	C Hirsch J Armes & E Banks co-applicants	Pending
Feasibility of a behavioural intervention to reduce fatigue in women undergoing radiotherapy for women with breast cancer	Tenovus	N Courtier J Armes J Hopkinson (SuPaC CSG) co-applicants	Successful
Lifestyle intervention for people following major resection for rectal cancer and given a temporary	Chief Scientist's Office (Scotland)	G Hubbard & Lifestyle sub group	Pending

stoma		E Banks as co-applicant	
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8. Collaborative partnership studies with industry

The Psychosocial Oncology & Survivorship CSG does not have any collaborative partnerships with industry.

9. Impact of CSG activities

The impact of clinical trials led by past or current members are summarised below.

Researchers at the University of Leeds (Velikova, Wright, Brown) have designed and developed new approaches and technologies for cancer patients to self-assess their symptoms and quality of life. The work focused on electronic methods for collecting patient-reported outcome measures (PROMs), developing PROMs for neglected areas of patient care, and running trials of these techniques (ePOCS, OPTIMAL). The team have also developed and tested a measure of social difficulties (SDI).

Contributing to clinical practice guidelines:

- Our research has influenced clinical guidelines internationally. For example, the trial demonstrating patient benefits from routine measurement of quality of life using automated measurement significantly contributed to clinical practice guidelines published in 2011 by the International Society for Quality of Life Research.
 - The SDI-21 was referenced in pan-Canadian clinical practice guidelines published in 2009 by the Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology.
 - The National Cancer Survivorship Initiative Vision, published in 2010 referenced SDI-21 as a questionnaire for assessing the quality of life of cancer survivors [C].

Changes in practice:

- The SDI-21 has been used in national evaluations of the quality of life of cancer patients and survivors [D]. It is also being used in the full national PROMs survey of 50,000 cancer patients during 2013. Internationally, the SDI-21 is being used in routine cancer practice in Canada as part of an electronic Distress Assessment and Response Tool and this has led to significant improvements in patient well-being.
- User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice. Version: November 11, 2011. Produced on behalf of the International Society for Quality of Life Research. Available at: <http://www.isoqol.org/research/isoqol-publications>.
- B. Howell, D., Currie, S., Mayo, S., Jones, G., Boyle, M., Hack, T., Green, E., Hoffman, L., Simpson, J., Collacutt, V., McLeod, D., and Digout, C. A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient, Toronto: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology, May 2009. Available at: <http://www.partnershipagainstcancer.ca/wp-content/uploads/2.4.0.1.4.6-AdultAssesmentGuideline122109.pdf>.

- C. Department of Health. Macmillan Cancer Support. NHS Improvement (2010). National Cancer Survivorship Initiative Vision. London, Crown. Available at: <http://www.ncsi.org.uk/wp-content/uploads/NCSI-Vision-Document.pdf>.
- D. Department of Health - Quality Health (2012). Quality of Life of Cancer Survivors in England: report on a pilot survey using Patient Reported Outcome Measures (PROMS). London, National Institute for Health Research. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127273/9284-TSO-2900701-PROMS.pdf.pdf.

10. Consumer involvement

We serve as the consumer members of the NCRI Psychosocial Oncology and Survivorship CSG and each of us acts as patient advisor on one of its subgroups. The third subgroup is supported by a fellow member of NCRI's Consumer Forum (Mr Chris Copeland).

We both regard this as an important means to develop and strengthen our experience and input. The support offered by mentors and other colleagues has ensured that our contributions are both meaningful and effective. Our input continues to be welcomed. It was clear from the outset that the differing skillsets from our careers, plus our consumer perspectives, help us bring an alternative approach or viewpoint in discussions. We are well integrated in the group's work and valued as equal contributors. Led by the Chair, Jo Armes, all our CSG colleagues understand the benefits and positive impact of patient advisor membership. They both respect and welcome our contributions as co-researchers and collaborators, the experience we bring as a result of our involvement in work across the UK and our genuine interest in supporting all aspects of the work of the Group.

Carolyn Morris:

- As a member of the Interventions Subgroup and the Breast Cancer CSG's Symptom Management Working Group.
- As a co-applicant for funded studies: eRapid and studies on fatigue, exercise and fear of recurrence; and for applications in development on recording consultations and linking experience and outcomes data.
- On Trial Management Groups for FASTForward and Restore.
- Patients' experience of research: I chair a multidisciplinary group of researchers, policy staff and consumers, analysing responses to questions about research in the English National Cancer Patient Experience Survey. Lead author on posters at NCRI and NCIN (National Cancer Intelligence Network) in 2015, demonstrating variations in patient access to conversations about research and an association between participation and better experience of care.
- Invited to present to the Independent Cancer TaskForce for England in 2015 on patient experience and access to research.
- I am mentored by Lynn Calman but am also supported by Jo Armes (Chair) and Elspeth Banks (Consumer Member).

Elsbeth Banks:

- As a consumer member of clinical trials committees at the Beatson WOSCC - the Clinical Trials Executive Committee, In-house Trials Advisory Board and sole independent member of Umbrella Trials Steering Committee.

- As a co-applicant on funding applications and steering group/trial management team member or advisory group member of a number of clinical trials and intervention studies such as EFFECT, MENAC, CEPAT, PRESCRIBE, MiniAFTER, She'L, Proact.
- As a member of the ECMC PPI Strategy Group.
- As a member of CRUK Patient Data Reference Group.
- As a member of a Cancer and Nutrition NIHR Infrastructure Collaboration Workstream.
- Am 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, the Scottish Cancer Patient Experience Quality Performance Indicators and Evaluating Cancer Services across Scotland, Wales and Northern Ireland.
- As a supporter of and contributor to PPI training and involvement events.
- I am mentored by Gill Hubbard but am also supported by Jo Armes (Chair) and Carolyn Morris (Consumer Member).

11. Open meetings/annual trials days/strategy days

The Group has not held any open meetings or annual trials days in the reporting year.

12. Priorities and challenges for the forthcoming year

Priorities:

- Increase the number of CSG-initiated studies developed
- Establish closer working relationship with sub-speciality leads and clinical trials units
- Develop mechanisms to collect information providing evidence of clinical practice impact

Challenges:

- Funding for POS research is limited and very competitive
- Mechanisms for research support differ in the devolved nations. This has meant that some studies have not been conducted outside England.
- Attributing the costs of health and social care Research and Development (AcoRD) changes have made it more difficult to get studies off the ground as
 - Costs of hosting trials now go into applications – consequently there is less to go round.
 - Service Support Costs (SCC) have become difficult to get in England, although this has not been the case in Wales: and they are not available in Scotland
 - NHS Treatment Costs can be problematic to negotiate. This refers to the patient care costs, which would continue to be incurred if the patient care service in question continued to be provided after the R&D study had stopped. This includes any therapy offered to patients by clinical staff. Gaining agreement to pay NHS Treatment Costs for Phase pragmatic trials is becoming increasingly difficult as NHS Trusts continue to be required to make stringent efficiency savings.

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 – Interventions to improve outcomes in people affected by cancer
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

Appendix 6 – Strengths & Weaknesses from the Psychosocial Oncology & Survivorship CSG 2016
Progress Review

Dr Jo Armes (Psychosocial Oncology & Survivorship CSG Chair)

Appendix 1

Membership of the Psychosocial Oncology & Survivorship CSG

Name	Specialism	Location
Professor Eila Watson	Chair in Supportive Cancer Care	Oxford
Dr Chris Barton*	Clinical Research Fellow	Liverpool
Dr Sarah Slater*	Clinical Research Fellow	Glasgow
Mrs Elspeth Banks	Consumer	Motherwell
Mrs Carolyn Morris	Consumer	Lewes
Dr Peter Hall	Medical Oncologist	Leeds
Professor Kinta Beaver	Chair in Cancer Nursing	Preston
Dr Hilary Plant	Joint Clinical Lead, Macmillan Support and Information Service	London
Dr Joanne Reid	Lecturer	Belfast
Professor Mary Wells	Chair in Cancer Nursing Research & Practice	Stirling
Professor Claire Foster	Chair in Psychosocial Oncology	Southampton
Professor Nick Hulbert-Williams	Chair in Behavioural Medicine	Chester
Dr Lesley Storey	Senior Lecturer	Belfast
Dr Jo Armes (Chair)	Senior Lecturer	London
Dr Lynn Calman	Senior Research Fellow	Southampton
Dr Gill Hubbard	Reader in Cancer Care	Stirling
Dr Rachel Taylor	Reader in Children & Young People's Healthcare/Senior Research Manager	London
Mr Matthew Nankivell	Statistician	London

* denotes trainee member

Membership of the Subgroups

Understanding and measuring consequences of cancer and its treatment Subgroup		
Name	Specialism	Location
Mr Chris Copland	Consumer	York
Professor Diana Greenfield	Chair in Cancer Survivorship	Sheffield
Dr Adam Glaser	Paediatric Oncologist	Leeds
Mr Mike Horton	Research Assistant	Leeds
Dr Jo Armes	Senior Lecturer	London
Dr Anna Gavin	Senior Lecturer	Belfast
Dr Derek Kyte	Senior Lecturer	Birmingham
Dr Anne Lanceley	Senior Lecturer	London
Dr Lynn Calman (Chair)	Senior Research Fellow	Southampton
Dr Rachel Taylor	Senior Research Manager	Stirling

Lifestyle and behavioural change Subgroup		
Name	Specialism	Location
Dr Sarah Slater*	Clinical Research Fellow	Glasgow
Mrs Elpeth Banks	Consumer	Motherwell
Professor Robert Thomas	Medical Oncologist	Cambridge
Dr Chloe Grimmett	Research Fellow	Southampton
Dr Gozde Ozakinci	Senior Lecturer	St Andrews
Dr Anna Campbell	Senior Lecturer	Surrey
Dr Jackie Gracey	Senior Lecturer	Ulster
Dr Abigail Fisher	Senior Research Associate	London
Dr Gill Hubbard (Chair)	Senior Research Fellow	Stirling
Ms Joanne Haviland	Statistician	Surrey

Interventions to improve outcomes in people affected by cancer Subgroup		
Name	Specialism	Location
Professor Nick Hulbert-Williams	Chair in Behavioural Medicine	Chester
Professor Eila Watson	Chair in Supportive Cancer Care	Oxford
Professor Mary Wells (Chair)	Chair in Cancer Nursing Research & Practice	Stirling
Ms Carolyn Morris	Consumer	Lewes
Dr Hilary Plant	Joint Clinical Lead, Macmillan Support and Information Service	London
Dr Peter Hall	Medical Oncologist	Leeds
Ms Brooke Swash	Research Associate	Chester
Dr Laura Ashley	Senior Lecturer	Leeds
Dr Gozde Ozakinci	Senior Lecturer	St Andrews
Dr Lesley Storey	Senior Lecturer	Belfast

*denotes trainee member

Appendix 2

CSG & Subgroup Strategies

A – Main CSG Strategy

Vision:

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.

The specific remit is:

- Develop and conduct psychosocial and survivorship research
- Encourage the development of psychosocial and survivorship research, either freestanding or linked to treatment trials within the NCRN.
- Work closely with all NCRI Clinical Studies Groups to develop site-specific psychosocial and survivorship research protocols/studies.
- Consider research protocols submitted to CTAAC or PBSC where the main outcome measures are within the field of psychosocial oncology and or survivorship.

Research themes/subgroups:

- Lifestyle & Behaviour Change.
- Interventions to improve outcomes in people affected by cancer.
- Understanding and measuring the consequences of cancer and its treatment.

Strategic objectives:

The goals set out below are what each group will collectively work together to achieve, although Group members will also continue to pursue their own research agenda. The goals have been classified as follows:

- Level 1: short term goals that can be achieved within 12 months (review current research and opportunities in the NCRI portfolio, develop research partnerships especially with other CSGs).
- Level 2: mid-term goals that can be achieved within 2-3 years (improve evidence base via new research, e.g. apply for funding/conduct a systematic review or submit for feasibility study funding).
- Level 3: long term goals that can be achieved in 3-5 years (generate a new coherent body of evidence, e.g. NIHR programme grant, HS&DR grant, HTA funding).

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

Overall objective:

To develop and conduct research to understand the experiences of people living with cancer, to identify the consequences of living with and beyond cancer, including psychosocial and/or physical consequences of treatment, whether shortly after treatment or in the longer term.

- Level 1:
 - To raise consequences of treatment on the agenda of funding organisations by documenting ongoing studies and identifying how research outputs in this area may be strengthened.
 - To encourage routine collection of quality of life data to better understand the experiences of people living with cancer.

- To seek funding for a systematic review on PROMS reporting in cancer clinical trials.
- Level 2:
 - To develop and refine questionnaires and outcome measures to understand needs and the impact of interventions/treatments on all aspects of living with and beyond cancer.
 - To undertake research to identify and understand the consequences of living with and beyond cancer, including psychosocial and/or physical consequences of treatment.
 - To seek funding for observational lymphoma study to run alongside phase III trial.
- Level 3: Subject to our successes at Level 2, we will apply for a programme grant.

C – Interventions to improve outcomes in people affected by cancer Subgroup Strategy

Overall Objective:

To improve the experiences and outcomes of those affected by cancer (patients, family members and carers) by developing and facilitating research that addresses the psychosocial and supportive care needs of these populations, including interventional research that develops individualised models of care and tests different modes of delivery.

- Level 1:
 - Identify populations with unmet needs for whom there is little evidence or effective psychosocial interventions.
 - Identify and adapt psychosocial interventions of potential relevance to cancer for which further evidence is required.
 - Provide expertise on intervention design and the appropriate integration of psychosocial aspects into future studies/trials.
 - Develop and optimise appropriate measures for use in psychosocial intervention research.
 - Identify opportunities for collaboration with other Subgroups and CSGs.
- Level 2:
 - Submit a proposal for funding to identify the specific patient experiences of lesbian and gay people diagnosed with cancer in order to develop a future intervention study.
 - Submit a proposal for funding to address the information needs of melanoma survivors at high risk of recurrence.
 - Submit a proposal for funding to develop and feasibility test of Acceptance & Commitment Therapy to improve distress in people treated for cancer.
 - Submit a proposal for funding for a psychosocial intervention to address problematic long-term eating and drinking difficulties in cancer survivors.
 - Submit a proposal for funding for research into supporting people on, and increasing adherence to, long-term medications for cancer.
- Level 3: Subject to our successes at Level 2, we will apply for a programme grant.

D – Lifestyle and behavioural change Subgroup Strategy

Overall aim:

To create new knowledge and guidance on lifestyle and behaviour change interventions that will influence policy and practice for secondary prevention of cancer and lead to improvements in health outcomes of people living with and beyond cancer.

- Level 1:

- Conduct systematic review of multi-component health behaviour interventions.
- Identify current prospective cohorts that include health behaviour.
- Identify existing datasets that have potential for secondary data analysis.
- Identify opportunities for collaboration with other CSGs to explore the possibility of adding a lifestyle/behavioural change component to studies currently being worked up.
- Level 2:
 - Submit proposal for research funding to develop a pragmatic health behaviour intervention using existing services.
 - Submit to other funders for further pilot/feasibility work.
- Level 3: Subject to our successes at Level 2, we will apply for a programme grant.

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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
Null	All					
Instrument development	All				Symptom-based Q	
						HRQOL
		EORTC QL Cut-Of				
		ACCESSCare				
		eRAPID RCT in s				
		Generic EORTC Q				
					YoDA BRCA: Gene	
					eSMART: Randomi	
Living with cancer	All				A feasibility s	
		Exploring the i				
				PLACE		
		EORTC CAT Full Validation				
		Cancer Rehabilitation: Perceptions and attitudes				
Other	All	ACTION				
			Talking about HPV			Talking about HPV
						with breast cancer view
		The ENGAGE study				
		CanACT				
		clinical decision making				
		Fertility preservation				
Symptoms and side effects	All				FAST-Forward	
			Physical activ.	Physical activ.		Physical activ.
					Breast Recon. QoL	

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

■ Open Multi CSG Null
■ Open Single CSG

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
Instrument development	All		Open Single CSG Symptom-based Q			
Living with cancer	All		Open Multi CSG Multi myeloma			
		Open Single CSG A feasibility s				
Other	All	Open Multi CSG Talking about HPV		Open Multi CSG Talking about HPV		
				Open Multi CSG EORTC H&N		
					Open Single CSG RCRT: Feasibili	Open Multi CSG eSMART: Randomi
Symptoms and side effects	All		Open Multi CSG Physical activ.			Open Multi CSG Physical activ.
Transition from active therapy	All	Open Multi CSG 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	Testicular
Instrument development	All				Symptom-based Q
Living with cancer	All	A feasibility s			A feasibility s
Symptoms and side effects	All	PROPOSE			
		Physical activ.			

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

- Open Multi CSG
- Open Single CSG
- Null

Appendix 4

Publications in the reporting year

PROSPECTIV trial

Watson, E., Shinkins, B., Frith, E., Neal, D., Hamdy, F., Walter, F., Weller, D., Wilkinson, C., Faithfull, S., Wolstenholme, J., Sooriakumaran, P., Kastner, C., Campbell, C., Neal, R., Butcher, H., Matthews, M., Perera, R. and Rose, P. (2015), Symptoms, unmet needs, psychological well-being and health status in survivors of prostate cancer: implications for redesigning follow-up. *BJU International*. doi: 10.1111/bju.13122

RESTORE: An exploratory randomised controlled trial of an online intervention to enhance confidence to manage problems associated with cancer related fatigue following primary cancer treatment

Foster C, Grimmett C, May CM, Ewings S, Myall M, Hulme C, Smith PW, Powers C, Calman L, Armes J, Breckons M, Corner J, Fenlon D, Batehup L, Lennan E, May CR, Morris C, Neylon A, Ream E, Turner L, Yardley L, Richardson A. A web-based intervention (RESTORE) to support self-management of cancer-related fatigue following primary cancer treatment: a multi-centre proof of concept randomised controlled trial. 2015. *Supportive Care in Cancer*, 1-9. DOI:10.1007/s00520-015-3044-7.

Myall M, May CR, Grimmett C, May CM, Calman L, Richardson A, Foster CL. RESTORE: an exploratory trial of a web-based intervention to enhance self-management of cancer-related fatigue: findings from a qualitative process evaluation. *BMC Informatics and Decision Making*. 2015. Volume 15 (94). DOI:10.1186/s12911-015-0214-y.

RfPB study for web-based surgical decision aid

Recio-Saucedo A, Gerty SM, Foster CL, Eccles DM, Cutress RI. Information requirements of young women with breast cancer treated with mastectomy or breast conserving surgery: A systematic review. 2016. *The Breast*, 25:1-13. DOI:10.1016/j.breast.2015.11.001.

ePOCS feasibility study

Hall P, Hamilton P, Hulme C, Meads D, Jone sH, Newsham A, Marti J, Smith AJ, Masons H, Velikova G, Ashley L , Wright P. (2015) Costs of cancer care for use in economic evaluation: A UK analysis of patient-level routine health system data. *British Journal of Cancer*.;112:948-56 doi: 10.1038/bjc.2014.644

RESTORE: Online trial to support people with cancer related fatigue

Foster C., Calman L., Grimmett C., Breckons M., Cotterell, P., Yardley L., Joseph J., Hughes S., Jones R., Leonidou, C., Armes J., Batehup, L., Corner J., Fenlon D., Lennan E., Morris, C., Neylon, A., Ream E., Richardson , A., Turner, L. (2015). Managing fatigue after cancer treatment: Development of RESTORE an online resource to support self-management. *Psycho-Oncology*, 24:940-949. DOI:10.1002/pon.3747

Myall, M., May, C.R., Grimmett, C., May, C., Calman, L., Richardson, A., Foster, C. (2015) RESTORE: an exploratory trial of a web-based intervention to enhance self-management of cancer-related fatigue: findings from a qualitative process evaluation. *BMC Medical Informatics and Decision Making*, 15: 94. DOI: 10.1186/s12911-015-0214-y

Development of a HRQOL questionnaire for cancer patients with cachexia

Wheelwright SJ; Johnson CD. Patient-reported outcomes in cancer cachexia clinical trials. *Current Opinion in Supportive & Palliative Care*. 9(4):325-32, 2015.

Development of a HRQOL questionnaire module for anal cancer patients

Sodergren SC; Vassiliou V; Dennis K; Tomaszewski KA; Gilbert A; Glynn-Jones R; Nugent K; Sebag-Montefiore D; Johnson CD; EORTC Quality of Life Group. Systematic review of the quality of life issues associated with anal cancer and its treatment with radiochemotherapy. *Supportive Care in Cancer*. 23(12):3613-23, 2015.

Quality of life in multiple myeloma and follicular lymphoma

Osborne TR; Ramsenthaler C; Schey SA; Siegert RJ; Edmonds PM; Higginson IJ. Improving the assessment of quality of life in the clinical care of myeloma patients: the development and validation of the Myeloma Patient Outcome Scale (MyPOS). *BMC Cancer*. 15:280, 2015.

ACU.FATIGUE

Mackereth P, Farrell C, Bardy J, Molassiotis A, Finnegan-John J. Legitimising fatigue after breast-cancer treatment. *Br J Nurs*. 2015 Feb;24 Suppl 4:S4-S12. doi: 10.12968/bjon.2015.24.Sup4.S4.

Bardy J, Mackereth P, Finnegan-John J, Molassiotis A. Training in self-needling and performing it as part of a clinical trial: the practitioner and patient experience. *Acupunct Med*. 2015 Mar 6. pii: acupmed-2014-010708. doi: 10.1136/acupmed-2014-010708.

Depression and anxiety in prostate cancer

Watts S; Leydon G; Eyles C; Moore CM; Richardson A; Birch B; Prescott P; Powell C; Lewith G. A quantitative analysis of the prevalence of clinical depression and anxiety in patients with prostate cancer undergoing active surveillance. *BMJ Open*. 5(5):e006674, 2015.

Mindfulness for Fatigue in Breast cancer

Eyles C; Leydon GM; Hoffman CJ; Copson ER; Prescott P; Chorozioglou M; Lewith G. Mindfulness for the self-management of fatigue, anxiety, and depression in women with metastatic breast cancer: a mixed methods feasibility study. *Integrative Cancer Therapies*. 14(1):42-56, 2015 Jan.

Barriers to early diagnosis with breast cancer

Jones, C.E., Maben, J., Lucas, G., Davies, E.A., Jack, R.H. and Ream, E. Barriers to early diagnosis of symptomatic breast cancer: a qualitative study of Black African, Black Caribbean and White British women living in the UK. *BMJ open*, 5(3), 2015. p.e006944.

Reducing Fatigue Through Telephone Support

Ream E, Gargaro G, Barsevick A, Richardson A (2015) Management of cancer-related fatigue during chemotherapy through telephone motivational interviewing: Modeling and randomized exploratory trial. *Patient Education and Counselling*, 98(2), 199-206

Managing hot flushes and night sweats following prostate cancer

Stefanopoulou E, Yousaf O, Grunfeld EA, and Hunter MS. A randomised controlled trial of a brief cognitive behavioural intervention for men who have hot flushes following prostate cancer treatment (MANCAN). *Psychooncology* 2015, DOI: 10.1002/pon.3794

Yousaf O, Grunfeld EA, Hunter MS A systematic review of the factors associated with delays in medical and psychological help-seeking among men. *Health Psychology Review* 2015, 9(2), pp.264-276.

MENOS 1

Mewes JC, van Harten WH, Duijts SFA, Oldenburg HSS, van Beurden M, Stuiver MM, Hunter MS, Kieffer JM, Steuten LMG, Aaronson NK. Cost-effectiveness of cognitive-behavioral therapy and physical exercise for alleviating treatment-induced menopausal symptoms in breast cancer patients. *J Cancer Survivorship* 2015 9, 1, 126-135.

Jayasena CN, Comninos AN, Stefanopoulou E, Buckley A, Narayanaswamy S, Izzi-Engbeaya C, Abbara A, Ratnasabapathy R, Mogford J, Ng N, Sarang Z, Ghatei MA, Bloom SR, Hunter MS, Dhillon WS. Neurokinin B Administration Induces Hot Flashes in Women. *Scientific Reports Nature Group* 2015, 5, 8466. DOI:10.1038/srep08466.

Feedback of trial results

Bancroft E, Castro E, Arden-Jones A, Moynihan C, Page E, Taylor N, Eeles R, Rowley E, and Cox K. The psychological impact of undergoing genetic risk profiling in men with a family history of prostate cancer *Psycho-Oncology* 2015.

BRIGHTLIGHT: The 2012 TYA Cancer Cohort Study

Vindrola-Padros C, Taylor RM, Lea S, Hooker L, Pearce S, Whelan J, Gibson F. (in press) How do young people, their families and staff describe specialized cancer care in England? *Cancer Nursing* 2015

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 L, Solanki A, Hooker L, Carluccio A, Pye J, Jeans D, Frere-Smith T, Gibson F, Barber J, Raine R, Stark D, Feltbower R, Pearce S, Whelan J. (2015) Development and validation of the BRIGHTLIGHT Survey, a patient-reported outcome measure for young people with cancer. *Health and Quality of Life Outcome* 13: 107

Taylor RM, Mohain J, Gibson F, Solanki A, Whelan J, Fern LA. (2015) Novel participatory methods of involving patients in research: naming and branding a longitudinal study, BRIGHTLIGHT. *BMC Medical Research Methodology* 15: 20. doi: 10.1186/s12874-015-0014-1

Macmillan study of the family management of cancer cachexia syndrome

Hopkinson J, Richardson A. (2015) A mixed-methods qualitative research study to develop a complex intervention for weight loss and anorexia in advanced cancer: The Family Approach to Weight and Eating (FAWE). *Palliative Medicine*. 29, 164-176.

eSMART

Miaskowski, C., Cooper, B.A., Aouizerat, B., Melisko, M., Chen, L.M., Dunn, L., Hu, X., Kober, K.M., Mastick, J., Levine, J.D. and Hammer, M., 2016. The symptom phenotype of oncology outpatients remains relatively stable from prior to through 1 week following chemotherapy. *European journal of cancer care*. Published online: 18 Jan 2016 DOI: 10.1111/ecc.12437

Development of an EORTC disease or domain specific quality of life Questionnaire Phases I/II & III - The European organization for research and treatment of cancer – satisfaction with cancer care questionnaire: revision and extended application development

Anne Brédart, Ariane Beaudeau, Teresa Young, Hugo Moura De Albuquerque Melo, Juan Ignacio Arraras, Liz Friend, Heike Schmidt, Krzysztof A. Tomaszewski, Mia Bergenmar, Amélie Anot, Anna Costantini, Frédéric Marchal, Iwona M. Tomaszewska, Vassilios Vassiliou, Wei-Chu Chie, José Hureaux, Thierry Conroy, John Ramage, Franck Bonnetain, Dagmara Kulis, Neil K. Aaronson and EORTC Quality of Life Group Article first published online: 13 APR 2016 | DOI: 10.1002/pon.4127 – Psycho-Oncology

YoDA BRCA: Development and pilot testing of a web-based Genetic Testing Decision Aid for young women newly diagnosed with early stage breast cancer

FOSTER, C., RECIO-SAUCEDO, A., GRIMMETT, C., CUTRESS, R., ECCLES, D., ARMSTRONG, A., GERTY, S., TURNER, L., MASON, S., COPSON, E., ECCLES, B., EVANS, G. & AHMED, M. 2015. Webbased decision aids to support young women with breast cancer. *Psycho-Oncology*, 24, 4-5.

GRIMMETT, C., BROOKS, C., RECIO-SAUCEDO, A., CUTRESS, R., COPSON, E., EVANS, G., GERTY, S., ARMSTRONG, A., TURNER, L., 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. *Psycho-Oncology*, 25, 10-11.

GRIMMETT, C., PICKETT, K., SHEPHERD, J., WELCH, K., RECIO-SAUCEDO, A., STREIT, E., SEERS, H., TURNER, L ARMSTRONG, A., CUTRESS, R I., EVANS, G D., COPSON, E., MEISER, B., ECCLES, D & FOSTER, C. Systematic review of the empirical investigation of resources to support decision making regarding BRCA1 and BRCA2 genetic testing at the time of breast cancer diagnosis. Under review *Journal of Genetic Counselling* April 2016

CREW cohort study

Foster, C., Haviland, J., Winter, J., Grimmett, C., Seymour, K.C., Batehup, L., Calman, L., Corner, J., Din, A., Fenlon, D. and May, C.M., 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), p.e0155434.

Appendix 5

Major international presentations in the reporting year

There were no presentations during this reporting period.

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Appendix 6

Strengths & weaknesses from the 2016 Progress Review

Strengths

- It was recognised that the CSG members have generated a large amount of activity and the CSG has taken steps since the last review to increase the scope of its activity to begin to include survivorship.
- The defined subgroup structure was noted.
- The Subgroup Chairs had a clear understanding of the work of their subgroups.
- The Subgroup Chairs and CSG members clearly represent key opinion leaders in the field of psychosocial oncology research.
- The funding success rate is good.
- The publication record of the CSG members is good.

Issues for the CSG to consider

- The report was a little repetitive and difficult to navigate; however it was acknowledged that this may, to some extent, reflect the limitations of the template.
- Reporting of CSG activity must reflect the collective work of the CSG, not be a sum of the individual research activities of the group.
- The group was encouraged to develop relationships with CTUs in order to enable development of large scale trials.
- The Panel encouraged the group to hold a Strategy Day in order to take forward their ideas and to develop a well formed strategy including a clear vision/mission for the group. This should consider:
 - Membership of the Group – are the right people involved
 - Connecting the CSG expertise with other areas of biological research that may be complementary/synergistic
 - Structure of the Group and its Subgroups
 - Succession planning and fostering of junior investigators for the future
 - How will interactions with other groups evolve and develop, including other NCRI CSGs and the Subspecialty leads based in the Networks
 - How the expert researchers involved with the CSG and Subgroups can come together to achieve outcomes that would not be feasible for a single researcher to achieve working alone, increasing the number of patients that could benefit
 - Novel areas for exploration, for example, the use of e-Health technologies
 - The Group's position in the international arena
- The Panel encouraged dissemination of the results of the research that the Group had pioneered into practice changing outputs.

Issues for the NCRI/NIHR CRN to consider

- How to encourage CSG Chairs to attend the NCRI Conference.
- Working with the POS CSG to ensure that appropriate studies are badged in the portfolio as POS CSG studies.