

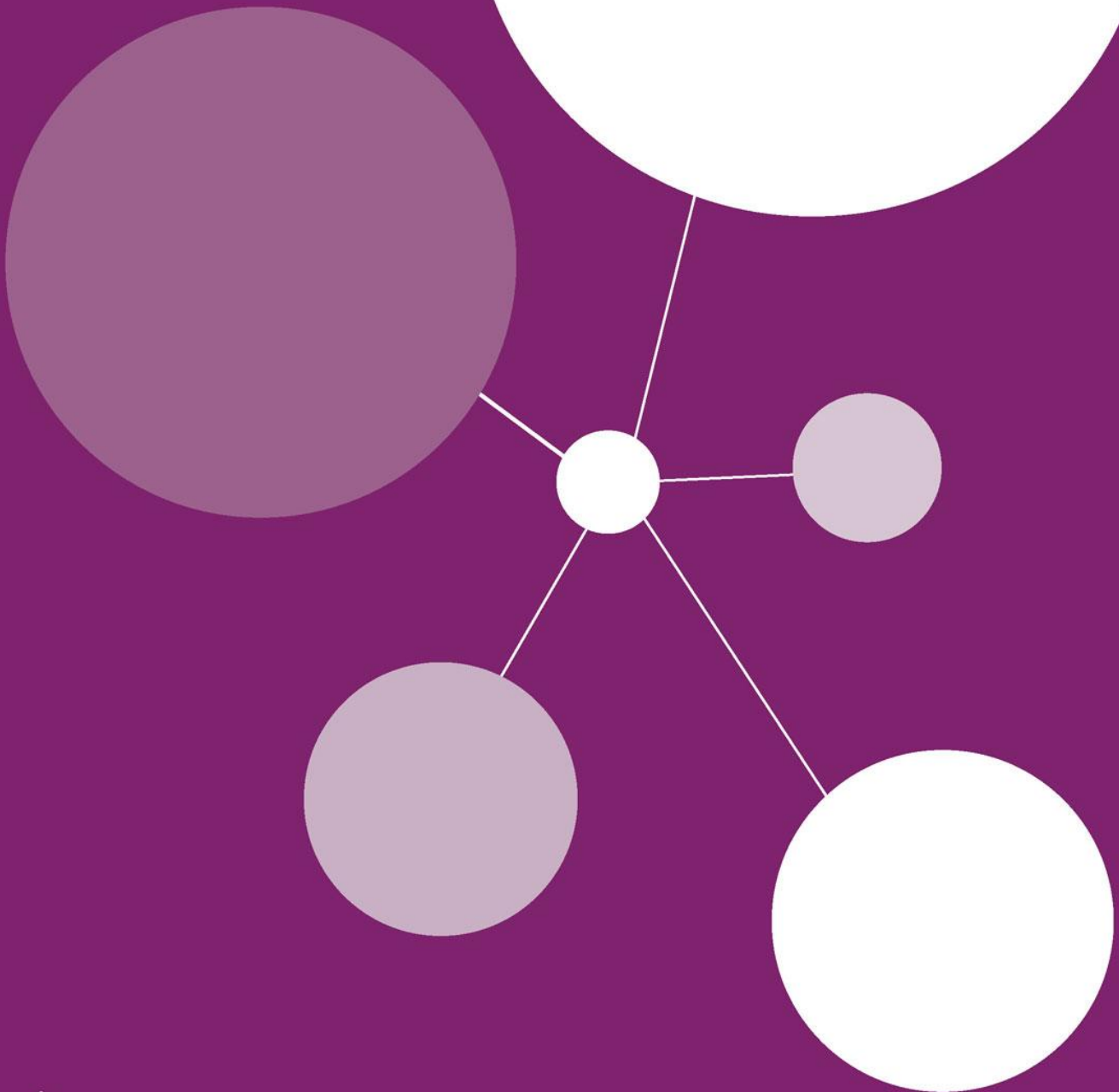


NCRI

National
Cancer
Research
Institute

NCRI Psychosocial Oncology & Survivorship Clinical Studies Group

Annual Report 2014/2015



Partners in cancer research



NCRI Psychosocial Oncology & Survivorship CSG Annual Report 2014/15

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 have presented the work of the CSG to the other CSGs and highlighted areas for potential future collaboration. As a consequence, representative of the CSG have been invited to attend the strategy days of a number of tumour specific CSGs. Requests for potential collaboration have increased markedly and a joint grant application has already been submitted. We aim to develop further collaborative research studies with colleagues from the other CSGs in the coming year.

The CSG subgroups have worked hard to initiate and develop their research ideas and this has culminated in the submission of a number of grant applications to both Government and charity funders. 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.

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 will shortly be appointing two trainees to the CSG, who will also contribute to the following subgroups 1) Understanding and Measuring Consequences of Cancer and its Treatment and 2) Lifestyle and Behavioural Change

In the last year Dr Hilary Plant and Dr Joanne Reid have joined the POS CSG. Dr Sundar Santhanam and Dr Chris Sutton have rotated off the CSG having helped the Group gain both clinical and methodological expertise through having both a clinical oncologist and a statistician in its membership.

Dr Jo Armes, Professor Kinta Beaver and Professor Nick Hulbert-Williams and Ms Carolyn Morris have had their membership to the CSG extended.

3. CSG & Subgroup strategies

Main CSG

Aims

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 to:

- Develop and conduct psychosocial and survivorship research
- Encourage the development of psychosocial and survivorship research, either freestanding or linked to treatment trials.
- 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 PRC where the main outcome measures are within the field of psychosocial oncology and or survivorship.

Achievements

In past 12 months the CSG has:

- Presented the work of the POS CSG to 95% of other CSGs; we anticipate that this will yield collaboration in the coming year.
- Responded to 5 Concept registrations forms submitted to the CSG, submitted 3 concept registrations and 6 grant applications - 1 grant has been awarded and we await results from 3 applications. Furthermore we have had 23 publications from portfolio projects.
- Continued to represent psychosocial oncology at a national level (e.g. our members lead the British Psychosocial Oncology Society, are on the Steering Committee of the Royal College of Nursing International Research Society Conference and present at a wide range of conferences, including NCRI) and international level (e.g. Professor Hulbert-Williams chairs The Research Committee of The International Psychosocial Oncology Society; Professor Mary Wells is Secretary of the Executive Board of the European Oncology Nursing Society.

Challenges

- Our main challenge continues to be lack of specific funding streams for psychosocial oncology research
- Agreeing the payment of NHS excess treatment costs under AcoRD continues to be a substantial challenge for non-pharmacological/behavioural intervention studies and hence is problematic for the type of research we conduct

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

Dr Taylor has been appointed as acting Chair to cover maternity leave.

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

Grants:

- Understanding patients' experience of living with sarcoma and using experience to improve services. (R Taylor & members of POS CSG)
- EPiC: **E**valuation of **P**atient-reported outcome protocol content and reporting **i**n UK **c**ancer clinical trials: a mixed-methods study. (Dr Kyte & subgroup members).

Consultation

- Attended Renal CSG strategy day - December 2014 (R Taylor).
- Attended TYA CSG strategy day - April 2015 (R Taylor).
- Dr Steve Daw - long-term follow up arm to a lymphoma study. (A Glaser).
- Dr Dan Stark - PROM for the AGCT 1531 study (D Kyte).
- Dr Ashok Nikapota – quality of life assessment in bladder cancer treatment trial (J Armes).
- Dr Marcia Hall - PROM for the METRO-NV study (A Lanceley).

Challenges

The group does not always have members with the specific expertise needed when approached for advice and collaboration e.g. outcome measure development.

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

Aim

The aim of the group is 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

The main achievement is that all members have collaborated on a grant proposal for funding from Breast Cancer Campaign, which was successful. The project start date is 1st July 2015 and is titled:

Exercise referral to fitness centre or cardiac rehabilitation for post-surgery breast cancer patients: Pilot single-arm trial with embedded process evaluation (EFFECT)

Further achievements include:

- Inclusion of Elspeth Banks, NCRI Consumer Liaison Forum. Elspeth continues to be an invaluable co-researcher on this group.
- Collaboration with Colorectal Cancer CSG on the CRIB study led by Dr Gill Hubbard (chair of the lifestyle and behaviour chance subgroup) and involving Dr Richard Adams and Dr Dawn Storey of the Colorectal CSG.
- Attended the Colorectal CSG Strategy Day (G Hubbard & C Foster)

Challenges

Our main challenge is lack of specific research funding for lifestyle and behaviour change.

Interventions to improve outcomes in people affected by cancer Subgroup (Chair, Dr Nick Hulbert-Williams)

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

Members of the Subgroup submitted three grant applications in the previous 12 months

- Acceptance and Commitment Therapy for cancer related distress (N Hulbert-Williams).
- RECORD (K Beaver): Recording oncology consultations for patient benefit: identifying and addressing barriers to implementation in practice.
- Information needs in melanoma patients (K Beaver).

Challenges

Our main challenge is lack of specific research funding for this type of research.

4. Task groups/Working parties

None have been convened by the POS CSG, however the CSG made a written contribution to the National Cancer Taskforce that was convened this year. In addition Dr Jo Armes and Ms Carolyn Morris attended discussion groups arranged by the National Cancer Taskforce.

5. Patient recruitment summary for last 5 years

In the POS CSG portfolio, 10 trials closed to recruitment and 13 opened. The number of people recruited to Psychosocial Oncology & Survivorship portfolio studies increased in 2014-2015. The number recruited to interventional studies was maintained at the same level as 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
2010/2011	1946	196	1916	196	-	-
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	-	-

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 the 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 & 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
- Professor Hulbert-Williams chairs The Research Committee of The International Psychosocial Oncology Society (IPOS)
- Professor Mary Wells is Secretary of the Executive Board of the European Oncology Nursing Society (EONS)

We co-hosted a sub-speciality meeting with the Supportive & Palliative Care CSG and these will be repeated on a regular basis.

7. Funding applications in last year

Table 3 Funding submissions in the reporting year

Other committees			
Study	Committee & application type	CI	Outcome
Exercise referral to fitness centre or cardiac rehabilitation for post-surgery breast cancer patients: Pilot single-arm trial with embedded process evaluation (EFFECT)	Breast Cancer Campaign, project grant	G Hubbard	Awarded
Acceptance and Commitment Therapy for cancer	NIHR RfPB North	N Hulbert-Williams	Pending

related distress	West, project grant		
Understanding patients' experience of living with sarcoma and using experience to improve services.	Sarcoma UK, project grant	R Taylor	Pending
EPiC: <u>E</u> valuation of <u>P</u> atient-reported outcome protocol content and reporting <u>i</u> n <u>U</u> K <u>c</u> ancer clinical trials: a mixed-methods study.	CRUK PRC, project grant	M Calvert & D Kyte	Pending
RECORD: Recording oncology consultations for patient benefit: identifying and addressing barriers to implementation in practice	NIHR HS&DR, programme grant	K Beaver	Not successful
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	Pending
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 McGowan	Not successful
Information needs in melanoma patients	NIHR RfPB North West, project grant	K Beaver	Not successful

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.

The programme of research undertaken by Professor Fallowfield and her team at The University of Sussex investigated health professionals' communication and comprehension about Phase I trials (Study ID: 4206). The research has impacted on the improvements in recruitment to clinical trials in two ways:

- it has been developed into material for training courses for cancer health professionals with national and international reach
- it has been used to support specific recruitment programmes for difficult trials including prostate, renal, breast and haematological cancers

In terms of training programmes over 200 facilitators from the UK, the USA and Canada have been trained to conduct courses using the communication about clinical-trials educational materials. These training courses were adopted by the English National Cancer Research Network (NCRN) and Welsh National Institute for Social Care and Health Research Clinical Research Centre (NISCHR). In Wales, 221 participants attended one of 25 'Talking about clinical trials' training courses between 2007 and 2012. Feedback from the courses was extremely positive, with participants indicating it changed their practice. The 32 NCRN Local Research Networks regions in England conducted 31 courses with 329 staff members between 2010–2012, again obtaining very positive participant feedback. As a result, there was a fivefold

increase in the recruitment of cancer patients to NCRN portfolio studies between 2001 and 2011, although an exact number attributable to the training alone cannot be specified.

Professor Myra Hunter has conducted a series of research studies aimed assessing and managing menopausal symptoms in people with breast and prostate cancer (Study ID: 4975; 10904). These trials of cognitive behaviour therapy (CBT) have important implications for clinical practice at a time when the use of hormone replacement therapy (HRT) has declined, and safe and effective non-hormonal options are being sought for breast cancer patients for whom HRT is usually contraindicated. CBT is one of the few effective alternatives to hormone therapy for hot flushes and night sweats; the interventions are brief and are more effective than other non-hormonal alternatives, such as exercise, yoga, relaxation, and some SSRIs. This research has been disseminated via international presentations, media coverage and publications. In addition it is being translated into clinical practice through the publication of a self-help book for women (Hunter & Smith 2013, Routledge) and a training manual for health professionals (Hunter & Smith 2014, Routledge) that is being used by counsellors/psychologists working in breast units and menopause clinics. Hunter & Smith are running sessions for breast cancer nurses and patients within an educational programme delivered by Breast Cancer Care.

10. Consumer involvement

Carolyn Morris

Ms Morris joined in June 2012 and contributes as follows:

- As a member of 1) Interventions to improve psychosocial outcomes in people affected by cancer Subgroup (POS CSG) & 2) Symptom Management Subgroup of the Breast CSG
- As a co-applicant for eRapid and studies on fatigue, exercise and fear of recurrence
- On the Trial Management Groups for FASTForward and Restore trials
- Lead author on two posters at NCIN exploring variations in patient access to conversations about research in the English National Cancer Patient Experience Survey. Both were selected for awards:
 - Morris C et al (2015). Keeping The Customer Satisfied - It's OK to Ask - So Who Are We Asking and Who Participates? Further Findings from the 2013 National Cancer Patient Experience Survey. NCIN Conference, Belfast. 8-10 June 2015 2nd place in Patient Reported Outcome/Experience Measures Awards
 - Morris C et al (2015). Keeping The Customer Satisfied - It's OK to Ask - Is Taking Part in Research Associated With Better Experience of Care? Findings from the 2013 National Cancer Patient Experience Survey. NCIN Conference Belfast 8-10 June 2015. 2nd place Patient Choice Award (Day 2).
- In her local Clinical Research Network (Kent, Surrey, Sussex); Clinical Senate of S.E. Coast Strategic Clinical Network and S.E Coast Research for Patient Benefit Committee

She is mentored by Dr Calman but is also supported by Dr Armes (Chair) and Ms Elspeth Banks (Consumer Member)

Mrs Elspeth Banks

Mrs Banks joined the Group in October 2013 and contributes as follows:

- As a Lifestyle and Behaviour Change Subgroup member

- 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 of a number of clinical trials and intervention studies such as EFFECT, MENAC, CEPAT, PRESCRIBE, ADJUNCT, miniAFTER, She'L
- As a trustee of Independent Cancer Patients Voice
- As a member of the ECMC PPI Strategy Group
- Is 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

She is mentored by Dr Hubbard but is also supported by Dr Armes (Chair) and Ms 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. Progress towards achieving the CSG's 3 year strategy

Steps towards achieving the CSG's 3 year strategy are detailed below:

- All three subgroups have submitted grant applications which they initiated and led
- The CSG completed a 'tour' of all the other CSGs to identify areas of mutual interest and explore the potential for collaboration on site-specific clinical trial development. This has resulted in an increase in the number of requests for collaboration and/or advice (n = 6)
- A collaborative grant application has been submitted to NIHR RfPB with representatives from the Bladder Cancer CSG

13. Priorities and challenges for the forthcoming year

Priorities for the POS CSG in the coming year are to:

- Continue to generate and submit CSG-led research studies for funding
- Increase cross-CSG collaboration on grant applications
- Establish strong working relationship with CRN Sub Speciality Leads

Challenges for the CSG will be:

- Securing research funding for psychosocial and survivorship research, which remains a challenge, however we will continue to investigate alternative funding streams
- Agreeing payment of NHS excess treatment costs under AcoRD continues to be a substantial challenge for non-pharmacological/behavioural intervention studies

14. Concluding remarks

The Psychosocial Oncology & Survivorship CSG has made substantial progress in implementing the 3 year strategy. The number of CSG initiated grant applications submitted for funding has increased, some of which were successful. The funding opportunities are limited for this type of cancer research and so we have made good progress in improving our links with other CSGs and developing collaborative grant applications.

15. 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 – Lifestyle and behavioural change Subgroup Strategy

D – Interventions to improve outcomes in people affected by cancer 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 Eila Watson	Chair in Supportive Cancer Care	Oxford
Mrs Elspeth Banks	Consumer	Motherwell
Mrs Carolyn Morris	Consumer	Lewes
Dr Peter Hall	Medical Oncologist	Leeds
Dr Sundar Santhanam	Medical Oncologist	Nottingham
Professor Kinta Beaver	Nurse	Preston
Dr Hilary Plant	Nurse	London
Dr Joanne Reid	Nurse	Belfast
Professor Mary Wells	Nurse	Stirling
Dr Claire Foster	Principal Research Fellow	Southampton
Dr Nick Hulbert-Williams	Psychologist	Chester
Dr Lesley Storey	Psychologist	Belfast
Dr Jo Armes (Chair)	Research Fellow	London
Dr Lynn Calman	Senior Research Fellow	Southampton
Dr Gill Hubbard	Senior Research Fellow	Stirling
Dr Rachel Taylor	Senior Research Manager	London
Dr Chris Sutton	Statistician	Preston

Membership of the Subgroups

Understanding and measuring consequences of cancer and its treatment Subgroup		
Name	Specialism	Location
Dr Isabel White	Clinical Research Fellow	London
Mr Chris Copland	Consumer	York
Dr Diana Greenfield	Nurse	Sheffield
Dr Adam Glaser	Paediatric Oncologist	Leeds
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

Interventions to improve outcomes in people affected by cancer Subgroup		
Name	Specialism	Location
Professor Eila Watson	Chair in Supportive Cancer Care	Oxford
Ms Carolyn Morris	Consumer	Lewes
Dr Peter Hall	Medical Oncologist	Leeds
Professor Kinta Beaver	Nurse	Preston
Professor Mary Wells	Nurse	Stirling
Dr Nick Hulbert-Williams (Chair)	Psychologist	Chester
Dr Lesley Storey	Psychologist	Belfast
Ms Brooke Swash	Research Associate	Chester
Dr Gozde Ozakinci	Research Fellow	St Andrews
Dr Laura Ashley	Senior Lecturer	Leeds

Lifestyle and behavioural change Subgroup		
Name	Specialism	Location
Professor Jane Wardle	Clinical Psychologist	London
Mrs Elpeth Banks	Consumer	Motherwell
Dr Michelle Harvie	Dietician	Manchester
Dr Gozde Ozakinci	Research Fellow	St Andrews
Dr Anna Campbell	Senior Lecturer	Surrey
Dr Jackie Gracey	Senior Lecturer	Ulster
Dr Abigail Fisher	Senior Research Associate	London
Professor Sally Haw	Senior Research Fellow	Stirling
Dr Gill Hubbard (Chair)	Senior Research Fellow	Stirling

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 to:

- 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, 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

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
2. To encourage routine collection of quality of life data to better understand the experiences of people living with cancer
3. To seek funding for a systematic review on PROMS reporting in cancer clinical trials

Level 2

1. 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.
2. To undertake research to identify and understand the consequences of living with and beyond cancer, including psychosocial and/or physical consequences of treatment
3. 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 – 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

1. Conduct systematic review of multi-component health behaviour interventions
2. Identify current prospective cohorts that include health behaviour
3. Identify existing datasets that have potential for secondary data analysis
4. 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

1. Submit proposal for research funding to develop a pragmatic health behaviour intervention using existing services
2. 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.

D – 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

1. Identify populations with unmet needs for whom there is little evidence or effective psychosocial interventions
2. Identify and adapt psychosocial interventions of potential relevance to cancer for which further evidence is required
3. Provide expertise on intervention design and the appropriate integration of psychosocial aspects into future studies/trials
4. Develop and optimise appropriate measures for use in psychosocial intervention research
5. Identify opportunities for collaboration with other Subgroups and CSGs

Level 2

1. 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
2. Submit a proposal for funding to address the information needs of melanoma survivors at high risk of recurrence
3. Submit a proposal for funding to develop and feasibility test of Acceptance & Commitment Therapy to improve distress in people treated for cancer
4. Submit a proposal for funding for a psychosocial intervention to address problematic long-term eating and drinking difficulties in cancer survivors.
5. 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.

Appendix 3

Portfolio maps

MAP A		PSYCHOSOCIAL ONCOLOGY & SURVIVORSHIP			YELLOW=OPEN/RECRUITING PURPLE=IN SET-UP/FUNDED CLEAR=MULTI-CSG STUDY; DASHED BORDER -IN SET-UP
Tumour Type	All cancers		Bladder	Brain	Breast
Symptoms & Side Effects	<p>CanTalk V3</p>				<p>LORIS</p> <p>EORTC Breast Reconstruction Quality of Life module - Phase 4</p> <p>REPORT-UK Phase 3</p> <p>REPORT-UK Phase 1</p> <p>FASTForward</p> <p>Value of PFS ALAVAPROFS</p>
Transition from Active Therapy	<p>REJOIN study</p>				
Living with Cancer	<p>Walking intervention for people with recurrent or metastatic cancer</p>		<p>Physical activity rehab for cancer survivors</p>		<p>MABCan</p> <p>Physical activity rehab for cancer survivors</p> <p>An expressive writing study for breast cancer patients</p>
Instrument Development	<p>EORTC Module to Assess Sexual Health in Cancer Patients</p> <p>EORTC Generic QL Phases I-III</p> <p>HRQOL Questionnaire for cachexia</p> <p>Computerised Adaptive Testing for EORTC QLQ-C30</p> <p>ACCESSCare Project</p> <p>Cancer and Dementia</p> <p>eRAPID RTC</p> <p>EORTC Cut-off scores</p>				<p>Creation of symptom-based questionnaires</p>
Other	<p>View & experiences of cancer screening</p> <p>ACTION: Patient involvement in medical decision</p>				<p>Lives at Risk</p>

(D): CSG-developed (C): CSG-consulted (O): Other (A): Academically-sponsored (P): Academic/Industry Partnership (I)

Developed by NCRI CSGs & NCRN

Version: October 2014

MAP B					
PSYCHOSOCIAL ONCOLOGY & SURVIVORSHIP					
YELLOW=OPEN/RECRUITING PURPLE=IN SET-UP/FUNDED CLEAR=MULTI-CSG STUDY; DASHED BORDER -IN SET-UP					
Tumour Type	Children's Cancer and Leukaemia	Colorectal	Gynaecological	Haem Onc	Head & Neck
Symptoms & Side Effects	<p>(C)(A) Reducing treatment related distress children leukaemia</p>	<p>(C)(A) REPORT-UK Phase I</p> <p>(D)(A) CRIB</p> <p>(C)(A) REPORT-UK Phase 3</p>	<p>(C)(A) REPORT-UK Phase I</p> <p>(C)(A) REPORT-UK Phase 3</p> <p>(C)(A) Value of PFS ALAVAPROFS</p>	<p>(C)(A) REPORT-UK Phase I</p> <p>(C)(A) REPORT-UK Phase 3</p>	<p>(C)(A) Value of PFS ALAVAPROFS</p>
Transition from Active Therapy			<p>(C)(A) OvPSYCH 2</p>		
Living with Cancer		<p>(C)(A) Physical activity rehab for cancer survivors</p>		<p>(C)(A) Physical activity rehab for cancer survivors</p> <p>(C)(A) Multiple myeloma lifestyle study</p>	
Instrument Development		<p>(C)(A) EORTC QoL in patients with Anal Cancer</p>		<p>(C)(A) Creation of symptom-based questionnaires</p>	
Other	<p>(C)(A) OPTIMAL</p>		<p>(C)(A) OPTIMAL</p>	<p>** : Suspended until further notice</p>	

(D): CSG-developed (C): CSG-consulted (O): Other (A): Academically-sponsored (P): Academic/Industry Partnership (I)

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MAP C		PSYCHOSOCIAL ONCOLOGY & SURVIVORSHIP			
		YELLOW=OPEN/RECRUITING PURPLE=IN SET-UP/FUNDED CLEAR=MULTI-CSG STUDY; DASHED BORDER -IN SET-UP			
Tumour Type	Lung	Lymphoma	Melanoma	Prostate	
Symptoms & Side Effects	<div style="border: 1px solid black; padding: 2px;"> C A REPORT-UK Phase I </div> <div style="border: 1px solid black; padding: 2px;"> C A ELCID </div> <div style="border: 1px solid black; padding: 2px;"> C A REPORT-UK Phase 3 </div>	<div style="border: 1px solid black; padding: 2px;"> C A REPORT-UK Phase I </div> <div style="border: 1px solid black; padding: 2px;"> C A REPORT-UK Phase 3 </div>	<div style="border: 1px solid black; padding: 2px;"> C A Value of PFS ALAVAPROFS </div>	<div style="border: 1px solid black; padding: 2px;"> C A REPORT-UK Phase I </div> <div style="border: 1px solid black; padding: 2px;"> C A REPORT-UK Phase 3 </div>	
Transition from Active Therapy					
Living with Cancer			<div style="border: 1px solid black; padding: 2px;"> C A Physical activity rehab for cancer survivors </div>	<div style="border: 1px solid black; padding: 2px;"> C A Physical activity rehab for cancer survivors </div>	
Instrument Development	<div style="border: 1px solid black; padding: 2px;"> O A EORTC LC13 Revision </div> <div style="border: 1px solid black; padding: 2px;"> O A NA-ILD Study </div>				
Other				<div style="border: 1px solid black; padding: 2px;"> C A OPTIMAL </div>	

D: CSG-developed
 C: CSG-consulted
 O: Other
 A: Academically-sponsored
 P: Academic/Industry Partnership
 I

Developed by NCR1 CSGs & NCRN

Version: October 2014

MAP D PSYCHOSOCIAL ONCOLOGY & SURVIVORSHIP					
YELLOW=OPEN/RECRUITING PURPLE=IN SET-UP/FUNDED CLEAR=MULTI-CSG STUDY; DASHED BORDER -IN SET-UP					
Tumour Type	Renal	Sarcoma	Teenage & Young Adults	Testis	Upper GI
Symptoms & Side Effects					<div style="border: 1px solid black; padding: 2px;"> D A ROCS </div> <div style="border: 1px solid black; padding: 2px; background-color: yellow;"> C A REPORT-UK Phase I </div> <div style="border: 1px solid black; padding: 2px; background-color: yellow;"> C A REPORT-UK Phase 3 </div>
Transition from Active Therapy					
Living with Cancer	<div style="border: 1px solid black; padding: 2px;"> C A Physical activity rehab for cancer survivors </div>		<div style="border: 1px solid black; padding: 2px;"> C A BRIGHTLIGHT </div>		
Instrument Development				<div style="border: 1px solid black; padding: 2px; background-color: yellow;"> C A PROMTEC </div>	<div style="border: 1px solid black; padding: 2px; background-color: yellow;"> O A HRQL after Surgery for Upper Gastrointestinal Tumours </div> <div style="border: 1px solid black; padding: 2px; background-color: yellow;"> O A Creation of symptom-based questionnaires </div>
Other				<div style="border: 1px solid black; padding: 2px; background-color: yellow;"> C A OPTIMAL </div>	

: CSG-developed C: CSG-consulted O: Other A: Academically-sponsored P: Academic/Industry Partnership I

Version: October 2014
Developed by NCR1 CSGs & NCRN

Appendix 4

Publications in the reporting year

A mixed methods investigation to develop a complex intervention to support the effective family-management of cancer cachexia related problems

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.

ACUFATIGUE The effectiveness of acupuncture and self-acupuncture in managing cancer-related fatigue in breast cancer patients: a pragmatic randomised trial

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.

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.

BRIGHTLIGHT

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

CANWalk

Harris, Jenny, Vicki Tsianakas, Emma Ream, Mieke Van Hemelrijck, Arnie Purushotham, Lorelei Mucci, James SA Green, Karen Robb, Jacquetta Fewster, and Jo Armes. "CanWalk: study protocol for a randomized feasibility trial of a walking intervention for people with recurrent or metastatic cancer." *Pilot and Feasibility Studies* 1, no. 1 (2015): 7. doi:10.1186/s40814-015-0003-5 [Epub ahead of print]

Making the EORTC QLQ-C30 interactive: Development of computerized adaptive testing (CAT) for EORTC QLQ-C30 dimensions

Thamsborg, L. H., Petersen, M. Aa., Aaronson, N. K., Chie, W.-C., Costantini, A., Holzner, B. et al (2014). Development of a lack of appetite item bank for computer-adaptive testing (CAT). *Support Care Cancer*, 23(6), 1541-1548.

Creation of symptom based questionnaires

Sodergren SC, White A, Efficace F, Sprangers M, Fitzsimmons D, Bottomley A, Johnson CD (2014). Systematic review of the side effects associated with tyrosine kinase inhibitors used in the treatment of gastrointestinal stromal tumours on behalf of the EORTC Quality of Life Group. *Critical Reviews in Oncology and Haematology*. 2014 Jul;91(1):35-46

CNS 2005 01: An in depth study over time on the effect of child and parent factors on the perceived quality of life of children treated for a brain tumour

Bull K, Lioffi C, Culliford D, Peacock J, Kennedy C on behalf of the Children's Cancer and Leukaemia Group (CCLG). Child-related characteristics predicting subsequent health-related quality of life in 8 to 14 year old children with and without cerebellar tumors: a prospective longitudinal study. *Neuro-Oncology Practice*, 2014, 1:114-122. doi:10.1093/nop/npu016 (Epub ahead of print)

CRIB

Hubbard, Gill, Anna Campbell, Zoe Davies, Julie Munro, Aileen V. Ireland, Stephen Leslie, Angus JM Watson, and Shaun Treweek. "Experiences of recruiting to a pilot trial of Cardiac Rehabilitation In patients with Bowel cancer (CRIB) with an embedded process evaluation: lessons learned to improve recruitment." *Pilot and Feasibility Studies* 1, no. 1 (2015): 15. doi:10.1186/s40814-015-0009-z [Epub ahead of print]

Development of a HRQOL questionnaire for cancer patients with cachexia

Wheelwright, S.J., Darlington, A.S., Hopkinson, J.B., Fitzsimmons, D., White, A. & Johnson, C.D. (2014) A systematic review to establish health-related quality-of-life domains for intervention targets in cancer cachexia. *BMJ Support Palliat Care*. doi:10.1136/bmjspcare-2014-000680 [Epub ahead of print]

ePOCS electronic Patient-reported Outcomes from Cancer Survivors (ePOCS): A 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. Costs of cancer care for use in economic evaluation: A UK analysis of patient-level routine health system data. *British Journal of Cancer*. 2015;112:948–56 doi: 10.1038/bjc.2014.644 (Epub ahead of print)

Ashley L, Smith AB, Jones H, Velikova G, Wright P. Traditional and Rasch psychometric analyses of the Quality of Life in Adult Cancer Survivors (QLACS) questionnaire in shorter-term cancer survivors 15 months post-diagnosis. *Journal of Psychosomatic Research*. 2014;77(4):322-9 doi: 10.1016/j.jpsychores.2014.07.007. (Epub ahead of print)

From clinical trials to clinical practice: an international survey of oncologists on health-related quality of life outcomes

Rouette J, Blazeby J, King M, Calvert M, Peng Y, Meyer RM, Ringash J, Walker M, Brundage MD. Integrating health-related quality of life findings from randomized clinical trials into practice: an international study of oncologists' perspectives. *Qual Life Res*, 2014 Nov 29. [Epub ahead of print]

Health Behaviours in Cancer Survivors

Grimmett C, Simon A, Lawson V, Wardle J. Diet and physical activity intervention in colorectal cancer survivors: a feasibility study. *Eur J Oncol Nurs*. 2015 Feb;19(1):1-6. doi: 10.1016/j.ejon.2014.08.006. (Epub ahead of print).

MENOS 2: Managing menopausal symptoms: MENOS2 a randomised control trial of cognitive behavioural interventions for menopausal symptoms

Chilcot J, Norton S, Hunter MS. Cognitive behaviour therapy for menopausal symptoms following breast cancer treatment: who benefits and how does it work? *Maturitas* 2014 May;78(1):56-61. doi: 10.1016/j.maturitas.2014.01.007. [Epub ahead of print]

Norton S, Chilcot J, Hunter MS. Cognitive behaviour therapy for menopausal symptoms (hot flushes and night sweats): moderators and mediators of treatment effects. *Menopause* 2014 Jun;21(6):574-8. doi: 10.1097/GME.000000000000095 [Epub ahead of print]

PROSPECTIV

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 (Epub ahead of print)

PROSPECTIV – a pilot trial of a nurse-led psychoeducational intervention delivered in primary care to prostate cancer survivors: study protocol for a randomised controlled trial. Watson E, Rose P, Frith E, Hamdy F, Neal D, Kastner C, Russell S, Walter FM, Faithfull S, Wolstenholme J, Perera R, Weller D, Campbell C, Wilkinson C, Neal R, sooriakumaran P, Butcher H, Matthews M. *BMJ Open* 2014; 4:5 e005186 doi:10.1136/bmjopen-2014-005186

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*. DOI: 10.1002/pon.3747 [Epub ahead of print]

Quality of life in multiple myeloma and follicular lymphoma

Osborne TR, Ramsenthaler C, Wolf-Linder S de, Pannell C, Siegert RJ, Edmonds PM et al. 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* 2015 Apr 14;15:280. doi: 10.1186/s12885-015-1261-6. [Epub ahead of print]

Osborne TR, Ramsenthaler C, Wolf-Linder S de, Schey SA, Siegert RJ, Edmonds PM et al. Understanding what matters most to people with multiple myeloma: a qualitative study of views on quality of life. *BMC Cancer* 2014;14:496.

Reducing fatigue in individuals with cancer undergoing chemotherapy through telephone support and education

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

Teams talking

Jenkins V, Farewell V, Farewell D, Darmanin J, Wagstaff J, Langridge C, Fallowfield LJ. Drivers and barriers to patient participation in RCTs. *British Journal of Cancer* 108, 1402-1407, 2013, doi:10.1038/bjc.2013.113

Jenkins V, Farewell D, Farewell V, Batt L, Wagstaff J, Langridge C, Fallowfield LJ Teams Talking Trials: Results of an RCT to improve the communication of cancer teams about treatment trials. *Contemporary Clinical Trials* 35(1): 43-51, 2013 doi:10.1016/j.cct.2013.02.003

Appendix 5

Major international presentations in the reporting year

BRIGHTLIGHT

Taylor RM [symposium lead]. BRIGHTLIGHT: a lesson in Collaboration. The following presentations at 2014 RCN International Research Society Conference Glasgow, Scotland, 3rd April 2014 .

1. Taylor RM, O'Hara C, Hooker L, Fern L, Whelan J on behalf of the BRIGHTLIGHT Team. Overview of collaboration: from academic to industry
2. Durkacz S, Taylor RM, Fern L, Whelan J on behalf of the BRIGHTLIGHT Team. Collaboration with researchers: bridging between trial and survey
3. Pye J, Fern L, Solanki A, Taylor RM on behalf of the BRIGHTLIGHT Team. Collaboration with Industry: survey validation & delivery
4. Fern L, Gibson F, Taylor RM, Solanki A, Whelan J on behalf of the BRIGHTLIGHT Team. Collaboration with young people: from consultant to co-researcher