



**NCRI**

National  
Cancer  
Research  
Institute

# **NCRI Psychosocial Oncology & Survivorship Clinical Studies Group**

**Annual Report 2017-18**



Partners in cancer research

## **NCRI Psychosocial Oncology & Survivorship CSG Annual Report 2017-18**

### **1. Top 3 achievements in the reporting year**

#### **Achievement 1**

We have identified the psychosocial oncology and survivorship portfolio by reviewing the entire NIHR portfolio and mapping it to previous research undertaken reviewing available research evidence in the field.

#### **Achievement 2**

The EPiC Study has reviewed the reporting of patient reported outcome measures on the NCRI trials portfolio and highlighted that a substantial proportion failed to report their patient-reported outcome (PRO) findings study. Results from the study will be used to make key recommendations to enhance the likelihood of successful delivery of PROs in the future.

#### **Achievement 3**

The Psychosocial Oncology & Survivorship (POS) CSG successfully raised the profile of the work of the POS CSG by hosting a very successful symposium at the British Psychosocial Oncology Society (BPOS) Annual Conference 2018.

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

The main CSG consists of 15 members from a variety of disciplinary backgrounds, two of whom are consumer members. The composition of the Group differs from site-specific CSGs in that most members are employed in the university sector rather than the NHS. Professor Galina Velikova was appointed CSG Chair in April 2018 as Dr Jo Armes rotated off the CSG. In the last year, Dr Derek Kyte and Professor John Saxton joined the POS CSG. Dr Derek Kyte currently chairs the Understanding & Measuring Consequences of Cancer & its Treatment Subgroup, taking over from Dr Lynn Calman who rotated off the CSG. Dr Armes and Dr Calman have made a significant contribution to the work of the CSG. Ms Carolyn Morris stepped down from the POS CSG in June 2017. Mrs Sue Restorick-Banks was welcomed as the new consumer representative in January 2018. Dr Jenny Harrington completed her trainee position on the CSG having led the mapping of the POS studies on the NCRI CSG.

### 3. CSG & Subgroup strategies

#### Main CSG

##### **Develop and undertake research which results in improved patient experience**

We have made significant progress in reviewing the use of Patient-Reported Outcome Measures (PROMs) in the NIHR portfolio (EPiC Study) and the results will be disseminated in the coming 12 months at key international scientific conferences including British Society of Gastroenterology (BSG), BPOS, NCRI, the UK PROMs conference and the International Society for Quality of Life conference in October. We are also hosting a joint meeting with the NCRI Consumer Forum at the University of Birmingham in July 2018. The last phase of the study concentrates on developing resources to promote improved reporting of PROMs in cancer clinical trials so they can be used to inform patient treatment decision making.

Two members of the CSG have been awarded funding from NIHR to explore the experience and outcomes for people with cancer who are serving a custodial sentence. This study aims to make recommendations about how care and support to this group of people can be improved.

##### **Work collectively as a team to develop proposals and seek funding for projects**

The POS CSG Subgroups have collaboratively developed and submitted proposals for funding with varying success – see Table 2 for full information.

##### **Actively seek collaboration with tumour-specific CSGs**

The CSG has broadened its collaborations with tumour specific CSGs as follows:

- Sarcoma CSG: A Sarcoma-specific PROM is being developed and has been included in the recently funded ICONiC study - a large biomarker study in osteosarcoma.
- Children's Cancer & Leukaemia (CCL) CSG: Little SAM - a version of SAM is being planned for use in patients aged 8-16 and parent proxy from birth onwards. This will be integrated as a companion study to the latest FaR-RMS study.
- Breast Cancer CSG: A joint application was successful in gaining funding from the Chief Scientist's Office (CSO) in Scotland to pilot the Mini-AFTERc intervention to manage fears of cancer recurrence in patients with breast cancer.
- Teenage and Young Adults & Germ Cell Tumour (TYA & GCT) CSG: A joint application was made to Macmillan Cancer Support to investigate the use of online digital technology to improve the experience and psychosocial outcomes of young people living with cancer
- Primary Care & POS CSG: A study was submitted for funding to Macmillan Cancer Support aimed at improving patient-centred outcomes following a diagnosis of cancer: enhancing the role of primary care

##### **Provide support and advise researchers working in this area**

We offer researchers the opportunity to gain feedback research proposals either by making a presentation at the main CSG meeting or via written feedback on funding applications.

### **Portfolio development**

We have recently completed a portfolio mapping exercise, with the support of trainee, Dr Jenny Harrington. This involved identifying all trials on the entire NIHR portfolio which measured psychosocial outcomes as a primary or secondary outcome. Three CSG members (Professor Mary Wells, Dr Hilary Plant & Dr Abigail Fisher) then mapped the existing studies with POS CSG outcomes to current priorities and gaps in evidence, in order to identify areas of current inactivity, which can be taken forward next year. This work will complement the results from the identification of research priorities for living with and beyond cancer which is being undertaken by the NCRI through a James Lind Alliance (JLA) Priority Setting Partnership (PSP) and will report late in 2018. Both will inform the future research strategy of the both the CSG and its subgroups.

### **Ensure successful delivery of studies through integration with NIHR CRN**

The CSG chair has participated in the newly convened Sub-Speciality Leads (SSLs) teleconference which takes place at 6 weekly intervals. The aim is to raise awareness of studies which have been recently adopted onto the portfolio as well as offer support for ongoing studies. The POS and Supportive & Palliative Care (S&PC) CSGs co-hosted a joint meeting with the SSLs on 14<sup>th</sup> December 2017 to discuss further development of the portfolio.

### **Strengthen UK and International working**

Following the very successful joint meeting with the BPOS in 2017 we were invited to co-host a meeting at the 2018 BPOS Annual Conference in Southampton. The aim of the session is to raise the profile of the CSGs work and to showcase the research on the POS portfolio. Speakers included Professor Diana Harcourt, Professor Emma Ream and Dr Ameeta Retzer. The feedback showed the session was well received with most rating it as excellent or very good.

### **Patient and Public Involvement**

Consumer involvement is welcomed by the CSG and our consumer representatives are valued as equal contributors and are fully integrated in the work of the Group. Our consumer representatives bring different skillsets which helps them to offer an alternative approach or viewpoint in discussions. CSG colleagues respect and welcome contributions from our consumer representatives as co-researchers and collaborators and the experience they bring. Consumers contribute fully to cancer research across the UK and have played a full and active part into the future strategy of the CSG and the proposed direction of research.

## Interventions to improve outcomes Subgroup (Chair, Professor Mary Wells)

### **Develop grant proposals for the development and evaluation of interventions to address priorities in living with and beyond cancer, as identified by the James Lind Alliance (JLA) Priority Setting Partnership (PSP)**

Over the past year the Subgroup submitted a collaborative grant application to Macmillan Cancer Support, to develop and test a digital intervention for fear of recurrence, but this was unsuccessful. Subgroup members continue to work on a range of psychosocial and survivorship outcome and intervention studies, and several 'subgroup involved' studies are ongoing or in development. There have also been some grant successes. The JLA PSP is due to report in November 2018 which will further inform our portfolio development.

### **Strengthen links with site specific CSGs and increase the number of collaborative intervention studies with meaningful psychosocial elements, with a particular focus on under-researched cancer groups**

The Subgroup has only met once during the reporting year mainly due to the Chair moving jobs. We have, however, had many email discussions and have been heavily involved in the work of developing the POS CSG Strategy.

### **Use the portfolio mapping exercise to identify gaps in evidence in relation to psychosocial interventions for particular cancer groups, and highlight these to existing funders**

Our trainee, Dr Jenny Harrington, completed a portfolio mapping exercise, identifying all trials on the entire NCRI portfolio, which measured psychosocial outcomes as a primary or secondary outcome. Two members of the group (Professor Wells and Dr Plant) have worked with Dr Fisher, on mapping the existing studies with POS outcomes to current priorities and gaps in evidence, in order to identify areas of current inactivity, which can be taken forward next year.

## Lifestyle and Behavioural Change Subgroup (Chair, Dr Abigail Fisher)

### **Develop and conduct studies (trials, cohorts or qualitative studies) to explore the role of lifestyle behaviours (physical activity, diet, smoking, alcohol, sun safety) after cancer diagnosis**

The Lifestyle and Behavioural Change Subgroup have submitted a number of applications including:

- The British Skin Foundation to assess teenagers and young adult cancer survivors understanding of their skin cancer risk.
- Yorkshire Cancer Research to test a mobile phone application to promote physical activity in cancer survivors.

**To conduct studies that explore how to embed appropriate health behaviour advice into the cancer care pathway**

Dr Chloe Grimmett is a co-investigator on a £2.3 million service transformation grant, funded by NHS England named Wessex fit-4-surgery trial (WesFit). This is a partnership with the Wessex Cancer Alliance, the Wessex Cancer Trust and the council to use exercise to improve patients' wellbeing before, during and after cancer treatment.

**To conduct trial and observational studies that demonstrate the impact of health behaviours on cancer outcomes (recurrence, survival)**

Members of the Subgroup (Dr Fisher & Dr Rebecca Beeken) were awarded funding from Cancer Research UK (CRUK) for the Advancing Survival Cancer Outcomes Trial: ASCOT. They have an invited submission to CRUK for the next phase of the ASCOT trial.

**Understanding and Measuring Consequences Subgroup (Chair, Dr Derek Kyte)**

**Ensure high quality patient-centred outcome data is available to help patients LWBC make more informed decisions around their care and support**

There is widespread acknowledgment of the importance of collecting/disseminating PRO data, such as quality of life and symptom burden, in cancer clinical trials. This data is important in supporting patients to make more informed treatment decisions at the point of cancer diagnosis and beyond.

The Subgroup is nearing completion of the 30-month Macmillan-funded EPiC project evaluating the rigor with which PRO data is currently incorporated in cancer clinical trials; and the potential barriers and facilitators to optimal PRO trial design, data collection and reporting. Our findings were alarming. Of 160 published cancer clinical trials collecting PRO data (2000 to 2014), and with a mean of 6.4 year's follow up from trial closure, 61 (38%) failed to report their PRO findings. Thus, valuable quality of life data and other PRO information may not be available to aid the decision-making of patients, clinicians and regulators. In addition, the completeness of PRO content in trial protocols was frequently inadequate, potentially impairing data collection and subsequent reporting. Even where PRO findings were published, there was often a significant delay, and reporting quality highly variable. These deficiencies must be urgently addressed to ensure important patient-centred data are made available to enhance clinical outcomes for the benefit of future patients. Our study provides a more detailed understanding of the potential barriers to optimal PRO trial design, data collection and reporting, alongside key recommendations to enhance the likelihood of successful delivery of PROs in the future.

**Inform health and care strategy through generation of robust patient-centred evidence**

The Sarcoma-specific PROM (S-PROM) study started in 2017. Phase 1, interview study with 121 patients is complete. Stage 2 is open to recruitment in 6 trusts and we have recruited 78 patients - the healthcare professional version will be circulated in the next couple of weeks. Presentations have been made at NCRI, SPAEN, BSG, RCN, ESMOS conferences. The sarcoma PROM (SAM) has been included in the recently funded ICONiC study - a large biomarker study in osteosarcoma – and we collect data at multiple time points to validate SAM for use

longitudinally. This is a collaboration with the Sarcoma CSG. Little SAM - a version of SAM is being planned for use in patients aged 8-16 and parent proxy from birth onwards. This will be integrated as a companion study to the upcoming FaR-RMS study. This is planned as a collaboration with the CCL CSG.

**Influence research strategy and funding priorities to focus on patient-centred outcomes**

The main manuscript for the EPiC study is currently under review with the British Medical Journal. The findings of the study will be disseminated at key international scientific conferences in 2018 including BSG, BPOS, NCRI, the UK PROMs conference and the International Society for Quality of Life conference in October. We are also hosting a joint meeting with the NCRI Consumer Forum group at the University of Birmingham in July 2018.

#### **4. Task groups/Working parties**

The Psychosocial Oncology & Survivorship CSG had no task groups or working parties during the reporting year.

## 5. Funding applications in last year

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

<b>Cancer Research UK Population Research Committee (CRUK PRC)</b>				
<b>Study</b>	<b>Application type</b>	<b>CI</b>	<b>Outcome</b>	<b>Level of CSG input</b>
<b>November 2017</b>				
Advancing Survival Cancer Outcomes Trial: ASCOT	Funded extension	Dr Abigail Fisher	Funded	CSG member (Fisher) is CI. Subgroup supported development of the application
<b>Other committees</b>				
<b>Study</b>	<b>Committee &amp; application type</b>	<b>CI</b>	<b>Outcome</b>	<b>Level of CSG input</b>
Developing and pilot testing an evidence-based psychological intervention to enhance wellbeing and aid transition into palliative care.	Macmillan Cancer Support Project Award	Dr Nick Hulbert-Williams	Funded	CSG members are CI and co-applicants (Dr Brooke Swash). Subgroup supported development of the application
Systematic review of effectiveness and cost-effectiveness of digital supportive interventions for people with cancer that cannot be cured.	Macmillan Cancer Support Project Award	Dr Mark Bagnall	Funded	CSG members (Ashley, Wells Hall) are co-applicants. Subgroup supported development of the application
A Pilot Trial of the Mini-AFTERc intervention to manage Fears of Cancer Recurrence in patients with breast cancer.	Chief Scientist's Office Project Award	Professor Gerry Humphris	Funded	CSG member (Armes, Banks) is co-applicant along with member of one of the Breast CSG subgroups. (Fenlon). Subgroup supported



				development of the application.
How is cancer care best provided to patients in English prisons? Assessing the disease burden in the prison population, experiences of diagnosis and support, and of receiving and providing cancer care.	NIHR Health Services and Delivery Research	Dr Ruth Davies	Funded	CSG members (Armes, Taylor) are co-applicants. Subgroup supported development of the application
Health Behaviour Change in Teenage and Young Adult Cancer Survivors	London Cancer Vanguard - Joint Research Fellowship	Dr Abigail Fisher, Dr Gemma Pugh	Funded	CSG members are CIs. Subgroup supported development of the application
Do teenagers and young adult cancer survivors understand their elevated risk of skin cancer?	British Skin Foundation Project Award	Dr Abigail Fisher	Pending	CSG members are CI and co-applicants (Dr Gill Hubbard, Banks, Pugh). Subgroup supported development of the application
Developing a new theory-driven online intervention to reduce fear of cancer recurrence in breast cancer survivors	Breast Cancer Now Project Award	Hirsch C	Pending	CSG member (Armes, Banks) is co-applicant. Subgroup supported development of the application.
Testing a mobile phone application to promote physical activity in cancer survivors	Yorkshire Cancer Research Project Award	Dr Abigail Fisher	Pending	CSG members are CI and co-applicant (Beeken). Subgroup supported development of the application
Lifestyle & Long-Term Health in Teenage and Young Adult Cancer Survivors: A Pan-London Cohort	Children with Cancer Project Award	Dr Abigail Fisher	Unsuccessful	CSG members are CI and co-applicant (Taylor). Subgroup supported development of the application

Beating Fatigue: Realising potential through app development	Macmillan Cancer Support Project Award	Dr Emma Ream	Unsuccessful	CSG member (Armes) is co-applicant. Subgroup supported development of the application.
CanWalk: community walking for people with advanced cancers, a multicentre randomised controlled trial	Macmillan Cancer Support Project Award	Dr Jo Armes	Unsuccessful	CSG member (Fisher) is co-applicant. Subgroup supported development of the application.
Fears of cancer recurrence: using digital technology to aid self-management	Macmillan Cancer Support Project Award	Dr Laura Ashley	Unsuccessful	CSG developed study
Global use of online digital technology to improve the experience and psychosocial outcomes of young people living with cancer	Project	Dr Nick Hulbert-Williams	Unsuccessful	Collaboration between the CSG (Hulbert-Williams) and TYA & GCT CSG (Edgar)
Improving patient-centred outcomes following a diagnosis of cancer: enhancing the role of primary care	Macmillan Cancer Support Project Award	Professor Eila Watson	Unsuccessful	Collaboration between the CSG (Watson) and Primary Care CSG (Watson)
Recording oncology consultations using a health care app	Macmillan Cancer Support Project Award	Professor Kinta Beaver	Unsuccessful	CSG members is CI. Subgroup supported development of the application
Supported self-management in cancer that cannot be cured: understanding and characterising its value and role	Macmillan Cancer Support Project Award	Dr Lynn Calman	Successful	CSG members is CI. Subgroup supported development of the application
Symptom appraisal following primary breast cancer: promoting timely presentation to health services with possible symptoms of recurrence	Macmillan Cancer Support Project Award	Professor Lucy Brindle	Unsuccessful	CSG members are CI and co-applicant (Watson). Subgroup supported development of the application
Trial of Optimal Personalised Care After Treatment – Gynaecological Cancer (TOPCAT-G)	NIHR Health Services and Delivery Research	Professor Valerie Morrison	Unsuccessful	CSG member (Watson) is co-applicant. Subgroup supported development of the application.

A systematic review and economic evaluation of the effectiveness of alternative strategies to hospital based follow-up after treatment for cancer	NIHR Health Technology Assessment	Professor Kinta Beaver	Unsuccessful	CSG members is CI. Subgroup supported development of the application
Assessing the acceptability and feasibility of a self-management support intervention for cancer patients due to start chemotherapy: A mixed methods feasibility study	Pan London Cancer Vanguard Joint Research Fellowship	Dr Hilary Plant	Unsuccessful	CSG members are CI and co-applicant (Armes). Subgroup supported development of the application
Health and well-being following surgery with curative intent: a prospective cohort	Roy Castle Lung Cancer Foundation Project Award	Professor Claire Foster	Successful	CSG members are CI and co-applicant (Calman). Subgroup supported development of the application

## 6. Consumer involvement

Consumer involvement continues to be welcomed from the Group and we are valued as equal contributors and are fully integrated in the work of the group. The different skillsets from our careers, in addition to our perspective as patients, help us to offer an alternative approach or viewpoint in discussions. Colleagues respect and welcome our contributions as co-researchers and collaborators and the experience we bring as a result of our involvement in work across the UK, our earlier careers and our genuine interest in supporting all aspects of the work of the Group. We have played a full and active part into the future strategy of the CSG and the proposed direction of research.

### **Elsbeth Banks**

I have served as a consumer member of the POS CSG since 2013, act as patient advisor on the Lifestyle and Behaviour Change Subgroup and am a member of the NCRI Consumer Forum. I will step down from the CSG in June 2018.

Both my scientific mentors on the CSG have also chaired my Subgroup, enabling an important means through which to develop and strengthen experience and input. This support offered by mentors and other colleagues has ensured that my contributions are both meaningful and effective. Positive working relationships have led to involvement in many activities both within and outwith NCRI, including chairing sessions and participating in conferences, regular requests to offer guidance on PPI involvement and invitations to be co-applicant/steering group/trial management group member across a broad range of clinical and academic trials.

These include: ACTwell, *Effect*, Macmillan HORIZONS, *FoR*, PROACT, *APP-AFTER*, Systems 2, Scotroc, Stratify, *Living with and beyond cancer with comorbid illness*, Cancer in the post-genomic era, *Individual and contextual levels of deprivation: an investigation of their influence on cancer outcomes and implications for cancer policy* and *Mave*

I have been invited to join the team on a CRUK Grand Challenge shortlisted project – Mining Medical Records for Early Signs of Cancer, led by Professor Henk van Weert - and am a co-investigator, serving on a Workstream and the Steering Group. I look forward to supporting the important development and contribution of an international collaboration of patients representing the six countries involved.

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

- Consumer member of clinical trials committees at the Beatson WOSCC (Clinical Trials Executive Committee), In-house Trials Advisory Board and sole independent member of Umbrella Trials Steering Committee.
- Trustee and active member of Independent Cancer Patients' Voice.
- Patient representative on the ECMC Strategy Advisory Group
- Member of Macmillan Horizons User Reference Group
- Member of the ECMC PPI Strategy Group.

- Invited regularly to review and offer comment on documents such as study protocols, study proposals, funding applications and patient information for both clinical trials and intervention studies.
- Patient representative on the Scottish Cancer Prevention Advisory Group
- Serve on two work streams for the NIHR Cancer and Nutrition Collaboration
- Delivered PPI input on PROMs and PREMs as part of a Cross-Innovation Cancer Challenge in Scotland.
- Provision of the patient/stakeholder component in a Research Impact MOOC at the University of Glasgow.

### **Sue Restorick-Banks**

I was appointed to the POS CSG in June 2017 with my first meeting being in January 2018. I will act as patient advisor on the Survivorship Subgroup and am a member of the NCRI Consumer Forum. Both my scientific mentor and the Chair of our CSG supported me in preparation for and beyond my initial CSG meeting. I have involvement in many activities within the umbrella of the NCRI and, for example, spoke at the recent Consumer Forum meeting about how the POS CSG can support and collaborate with other CSGs.

Some of my involvement that enhances my CSG work includes:

- Attendance at CREW Study Advisory Committee meetings.
- PPI representative on Macmillan Horizons User Reference Group
- Co-applicant of a successful application for a grant from Macmillan – Living with Cancer that cannot be cured. The Macmillan Survivorship group at the University of Southampton will carry out the study.

## 7. Priorities and challenges for the forthcoming year

<b><u>Priority 1</u></b> Increase the number of large scale national CSG-initiated studies developed.
<b><u>Priority 2</u></b> Expand collaborations with tumour-specific CSGs to develop and submit research proposals.
<b><u>Priority 3</u></b> Align the CSG strategy with the results from the NCRI Living and Beyond Cancer (LWBC) JLA PSP with gaps in the current NIHR portfolio and available research.
<b><u>Challenge 1</u></b> Allocation of studies to the POS CSG portfolio continues to be extremely challenging and since the initiation of the new contract with the co-ordinating centre, few studies have been added to our portfolio. This has significantly reduced the number of people recruited to our portfolio studies.
<b><u>Challenge 2</u></b> Funding for POS research continues to be limited and very competitive.
<b><u>Challenge 3</u></b> To develop a process for being informed at a very early stage of research proposals being developed by tumour specific CSGs.

## **8. Appendices**

Appendix 1 - Membership of main CSG and subgroups

Appendix 2 – CSG and Subgroup strategies

A – Main CSG Strategy

B – Interventions to improve outcomes Subgroup Strategy

C – Lifestyle and behavioural change Subgroup Strategy

D – Understanding and measuring consequences Subgroup Strategy

Appendix 3 - Portfolio Maps

Appendix 4 – Top 5 publications in reporting year

Appendix 5 – Recruitment to the NIHR portfolio in the reporting year

**Dr Jo Armes (Psychosocial Oncology & Survivorship CSG Chair)**

## Appendix 1

### Membership of the Psychosocial Oncology & Survivorship CSG

Name	Specialism	Location
Dr Richard Simcock	Clinical Oncologist	Brighton
Dr Rachel Taylor	Clinical Research Nurse	London
Mrs Elspeth Banks	Consumer	Carlisle
Mrs Susan Restorick-Banks	Consumer	Southampton
Professor Linda Sharp	Epidemiologist	Newcastle
Professor Eila Watson	Health Services Researcher	Oxford
Dr Hilary Plant	Information Specialist/Psychotherapist	London
Dr Derek Kyte	Health services Researcher	Birmingham
Mr Nicholas Lee (Observer)	Macmillan Research Lead	London
Dr Jennifer Harrington*	Medical Oncologist	Cambridge
Dr Peter Hall	Medical Oncologist/Health Economist	Edinburgh
Dr Feng Li	NCRI Programme Manager	London
Professor Joanne Reid	Nursing	Belfast
Dr Jo Armes (Chair)	Health Services Researcher/Nursing	London
Professor Mary Wells	Health Services Researcher/Nursing	London
Dr Abigail Fisher	Physiologist/Exercise Scientist	London
Professor John Saxton	Exercise Physiologist	Northumbria
Professor Claire Foster	Psychologist	Southampton
Dr Fiona Kennedy*	Psychologist	Leeds
Dr Lesley Storey	Psychologist	Belfast
Mr Matthew Nankivell	Statistician	London

\* denotes trainee member



## Membership of the Subgroups

<b>Interventions to improve outcomes Subgroup</b>		
<b>Name</b>	<b>Specialism</b>	<b>Location</b>
Ms Carolyn Morris	Consumer	Lewes
Dr Laura Ashley	Health Psychologist	Leeds
Professor Nick Hulbert-Williams	Health Psychologist	Chester
Dr Gozde Ozakinci	Health Psychologist	St Andrews
Dr Brooke Swash	Health Psychologist	Chester
Professor Eila Watson	Health Services Researcher	Oxford
Professor Mary Wells (Chair)	Health Services Researcher	London
Dr Hilary Plant	Information Specialist/Psychotherapist	
Dr Peter Hall	Medical Oncologist	Edinburgh
Dr Jennifer Harrington*	Medical Oncologist	Cambridge
Dr Lesley Storey	Psychologist	Belfast

<b>Lifestyle and behavioural change Subgroup</b>		
<b>Name</b>	<b>Specialism</b>	<b>Location</b>
Mrs Elspeth Banks	Consumer	Carlisle
Dr Chloe Grimmett	Health Psychologist	Southampton
Dr Gozde Ozakinci	Health Psychologist	St Andrews
Dr Gill Hubbard	Health Sociologist	Inverness
Dr Sarah Slater	Medical Oncologist	Glasgow
Professor Robert Thomas	Medical Oncologist	Bedford
Dr Abigail Fisher (Chair)	Physiologist & Exercise Scientist	London
Dr Jackie Gracey	Physiotherapist	Belfast
Dr Anna Campbell	Sport & Exercise Scientist	Edinburgh

<b>Understanding and measuring consequences Subgroup</b>		
<b>Name</b>	<b>Specialism</b>	<b>Location</b>
Dr Rachel Taylor	Clinical Research Nurse	London
Mr Christopher Copland	Consumer	York
Dr Derek Kyte (Chair)	Health Services Researcher	Birmingham
Dr Jo Armes	Health Services Researcher/ Nursing	London
Dr Lynn Calman	Health Services Researcher/ Nursing	Southampton
Dr Diana Greenfield	Health Services Researcher/ Nursing	Sheffield
Dr Anne Lanceley	Health Services Researcher/ Nursing	London
Professor Adam Glaser	Paediatric Oncologist	Leeds
Mr Mike Horton	Psychologist	Leeds
Dr Fiona Kennedy*	Psychologist	Leeds
Dr Anna Gavin	Public Health/Cancer Epidemiologist	Belfast

\* denotes trainee member

\*\*denotes non-core member

## Appendix 2

### CSG & Subgroup Strategies

#### A – Main CSG Strategy

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

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

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

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

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

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



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

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

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

## **B – Understanding and measuring consequences Subgroup Strategy**

### **Aims**

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

### **Objectives**

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

## **C – Interventions to improve outcomes Subgroup Strategy**

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

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

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

## **D – Lifestyle and behavioural change Subgroup Strategy**

### **Aims**

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

## Appendix 3

### Portfolio maps

NCRI portfolio maps							
Psychosocial Oncology and Survivorship							
Map A – All cancers, bladder, brain, breast, Children's cancer and leukaemia, colorectal							
Click ↓ below to reset map							
		All cancers	Bladder	Brain	Breast	Children's cancer and leukaemia	Colorectal
Instrument development	All						
		EORTC QL Cut/Of					
		eRAPID RCT in s					
		Generic EORTC Q					
					eSMART: Randomi	eSMART: Randomi	
		SPECTArare (EORTC 1553)					
		Predisposition					
Living with cancer	All						
		EORTC CAT Full Validation					
		Rehabilitation:					
		Outcome Measures					
						promoting physical	
Other	All						
		NIVO PASS					
		MePFAC					
					cancer risk materials		
Symptoms and side effects	All						
					FAST/Forward		
		HORIZONS			HORIZONS		
		Medical Radiation					
		The PAIR Study					
Transition from active therapy	All	monitoring					

Filters Used:  
Active Status: All, CSG Involvement: All, Funding Type: All, Phase: All, LCRN: None

In Setup / single re..
  Open / single rese..
  Open / multi resea..

Null



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## NCRI portfolio maps

### Psychosocial Oncology and Survivorship

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

Click ↓ below to reset map

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

Filters Used:

Active Status: All, CSG Involvement: All, Funding Type: All, Phase: All, LCRN: None

■ Open / single rese..  
■ Open / multi resea..  
■ Suspended / multi ..



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## NCRI portfolio maps

### Psychosocial Oncology and Survivorship

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

Click ↓ below to reset map

		Prostate	Renal	Sarcoma	Teenage and young adults	Testicular	Upper gastro-intestinal
Instrument development	All						
Living with cancer	All	INTERVAL - MCRPC v3.0			The young adult cancer patient journey		
Other	All						ROCS
Symptoms and side effects	All						
Transition from active therapy	All						

Filters Used:

Active Status: All, CSG Involvement: All, Funding Type: All, Phase: All, LCRN: None

Open / single rese..

Open / multi resea..



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## Appendix 4

### Top 5 publications in the reporting year

Please note that this section is incomplete

Trial name & publication reference	Impact of the trial	CSG involvement in the trial
1. <a href="#">Research priorities about stoma-related quality of life from the perspective of people with a stoma: A pilot survey</a> Hubbard G et al, <i>Health Expectations</i> (2017), 20 (6), pp. 1421-1427.	This reports results from a UK online pilot survey publicized in 2016 in which people ranked the importance of 9 stoma-related QoL topics. The results contribute to setting the research agenda for the study of stoma-related concerns that impact quality of life.	This is a CSG developed and led study.
2. <a href="#">Fear of cancer recurrence in oral and oropharyngeal cancer patients: An investigation of the clinical encounter.</a> Ozakinci G et al, <i>European Journal of Cancer Care</i> (2017)	This study investigated how healthcare professionals address recurrence fears, and how survivors experience this interaction. The results indicate that patients may feel reluctant to raise their FCR with their clinician for fear of appearing “ungrateful” or of damaging a relationship that is held in high esteem. Findings indicate the initiation of FCR with patients can be beneficial for patient support	The study was led by members of the CSG and supported during its development and conduct.
3. <a href="#">Social support following diagnosis and treatment for colorectal cancer and associations with health-related quality of life: results from the UK ColoRECTal Wellbeing (CREW) cohort study:</a>	The results show that social support declines following colorectal cancer diagnosis and treatment in nearly a third of patients and are an important risk factor for recovery of HRQoL. Assessment of support early on and throughout follow-up would	The CREW study was supported during its development by the CSG. Substantial support was provided by the CRN during the 5-year data collection period.

<a href="#">Social support after colorectal cancer. Haviland, J et al, Psycho-Oncology (2017), 26(12), 2276-2284.</a>	enable targeted interventions to improve recovery, particularly in the more vulnerable patient groups.	
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## Appendix 5

### Recruitment to the NIHR portfolio in the reporting year

In the Psychosocial Oncology & Survivorship CSG portfolio, 8 trials closed to recruitment and 10 opened.

#### 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
2013/2014	1360	306	1325	305	-	-
2014/2015	1919	310	1909	310	-	-
2015/2016	2649	374	2369	359	-	-
2016/2017	1095	541	713	496	-	-
2017/2018	2401	712	2190	692	-	-