

NCRI Primary Care Clinical Studies Group

Annual Report 2014/2015



Partners in cancer research



NCRI Primary Care CSG Annual Report 2014/15

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

This has been a year of progression and change for the NCRI Primary Care CSG. Professor Richard Neal has recently been appointed to Chair the Group, with Professor Clare Wilkinson stepping down after serving two terms. The activity of the Group has increased, with substantial new grants in progress, and trials beginning to report. Over the longer term, the group has overseen an exponential increase in capture of primary care patients into clinical trials (43 closed trials).

Our small and vibrant research community has grown in strength. The Group is populated by field leaders, who worked within national and international networks to ensure generation of high quality grant applications. We continued our strategy to support the design and development of randomised trials of complex interventions, and other high quality research including adaptive clinical trials, non-randomised trials, modelling studies, meta-analyses and observational studies including cohort, and cross sectional, and key secondary research. This is in keeping with NIHR commissioning.

A major challenge to our group remains the continued problem with the central capture of the primary care portfolio. After significant work to ensure capture last year, the latest portfolio figures are misleading once again, with over half of our studies missing. We request help from the NCRI Clinical Director to find an enduring solution.

2. Structure of the Group

We are delighted to welcome Professor Richard Neal as the new Chair of the Group. Dr Fiona Walters has stepped up to the role of Chair of the Early Diagnosis Subgroup. Dr Liz Mitchell, Senior Research Fellow Leeds University, has joined the group. We were delighted to welcome two new trainee members; Drs Nicola Thompson and Brian Nicholson who have had mentors appointed.

Professor Clare Wilkinson, Professor Willie Hamilton, Ms Natalie Billington and Professor Julietta Patnick will be stepping down from the Group in the spring 2015 membership rotations. Professor Nick Stuart and Dr Nick Hulbert-Williams also stepped down from the Group in the reporting year. Professor Eila Watson will take over the liaison role between the Primary Care and Psychosocial Oncology & Survivorship CSGs. Mr Paul Charlton (consumer member) also stepped down; we will miss his excellent patient focussed input. Ms Michelle Cox, Research Project

Officer, will be leaving the NCRI and therefore the Primary Care CSG and her work on the portfolio and mapping will be missed. Ms Natalie Billington also stepped down and we will miss her input into clinical networks. We look forward to making new appointments in the near future.

3. CSG & Subgroup strategies

Main CSG

Our strategy is to support the design and development of randomised trials of complex interventions, and other high quality research including adaptive clinical trials, non-randomised trials, modelling studies, meta-analyses and observational studies including cohort, and cross sectional, and key secondary research. We aim to increase recruitment to cancer trials and other high quality cancer research through primary care cohorts, both within our own CSG work and through broader collaborations (eg SPED, other CSGs). We will be holding a Strategy Day in November 2015 where this strategy will be revisited.

Survivorship Subgroup (Chair, Professor Eila Watson)

The key achievements of the Survivorship Subgroup are:

- PROPECTIV has completed, baseline data published all feasibility objectives met and trial findings being prepared for publication
- NIHR Programme grant application addressing health and wellbeing of cancer survivors in primary care (CLASP) is now in final stages of negotiation, with a view to funding.
- NIHR HSDR Project Grant Application, Examining the feasibility of a pharmacy intervention to increase adherence to adjuvant endocrine therapy in women diagnosed with breast cancer, prepared jointly with colleague from Psychosocial Oncology & Survivorship CSG and Breast CSG Symptom Management Working Group is now through to second round and final outcome awaited.
- Links established with Psychosocial Oncology & Survivorship, Testicular, Colorectal and Melanoma CSGs.
- Ran symposium at NCRI Conference 2014, 'Optimising role of primary care in cancer survivorship' with participation of Breast CSG Chair (past) Professor Alastair Thompson and a consumer representative, which was well-attended and well received and helped build the profile of our CSG and the work we do.

The strategy and aims of the Subgroup are outlined in Appendix 2B.

Screening Subgroup (Chair, Dr Christine Campbell)

The subgroup has met frequently throughout the year with ongoing email dialogue about development of ideas and proposals.

There have been changes in membership of this subgroup over the past 12 months: 1) Prof Paul Brocklehurst (University of Manchester, now at Bangor University) joined the subgroup in September 2014, bringing expertise in dental public health, 2) Dr Yoryos Lyratzopoulos (University of Cambridge, now at University College London) joined the subgroup late 2014 year bringing expertise in epidemiology primary care diagnostic pathways, and 3) Mrs Jan Rose joined the subgroup as consumer representative at the end of last year. We anticipate further changes and refreshing of subgroup membership in the coming months: we will seek greater involvement

of trainees and seek to continue to engage with colleagues in the NHS cancer screening programmes.

We will continue to support studies already in the portfolio: a number of NAEDI-funded projects are drawing to a close and will be written up over coming months; through Professor David Weller we will continue to engage on the ongoing trial of lung cancer screening led by Professor John Fields.

A number of research projects are in development and funding applications are planned over the several months. Professor Paul Brocklehust is leading on an oral cancer case detection study 'Determining the feasibility of an intervention to improve the case detection of potentially malignant disorders and early oral cancer by front-line health-care workers': this will be multicentre and multi-disciplinary. Ms Alison Clements is taking forward further qualitative work on experiences of patients following receipt of positive results in screening: earlier work from this subgroup has been on HPV triage, but new work on bowel screening especially in relation to flexible sigmoidoscopy is planned. Dr Campbell is leading descriptive work to compare development and implementation of cancer screening policies across the UK.

We recognise the need to build stronger collaborations with other CSGs, in particular Colorectal, Breast, Gynaecological and Lung CSGs, and with the Screening, Prevention & Early Diagnosis (SPED) Advisory Group. Dr Campbell is working with Professor Neal as the incoming Chair of the Primary Care CSG to take forward these links.

Early Diagnosis Subgroup (Chair, Professor Richard Neal)

Much of the emphasis of this year has been in delivering on current portfolio studies (for example CANDID, ICBP4, MelaTools and SYMPTOM), and in planning longer terms projects and programmes. Two specific programmes are in planning for submission later this year. One will focus on the diagnosis of abdominal cancers and the other on the development of a suite of interventions to reduce primary care intervals. Various members of the subgroup are involved in the planning of phase II of the International Cancer Benchmarking Partnership.

We have expanded our connections with other CSGs. Most progress has been made with the Skin CSG, and we have re-established good links and plans for collaboration with Lung, Colorectal, TYA and Prostate CSGs. We will continue to engage with the Molecular Biomarkers Advisory Group to take this important agenda forwards. We have made significant input into the SPED Advisory Group, ensuring a robust primary care input, and increasing the quality of the proposals coming that group. Two proposals (CHEST and MelaTools) have been favourably discussed at SPED.

Further proposals are being developed on: emergency presentation of cancer, and how it can be prevented; examining system and cognitive factors relating patient safety issues in the diagnostic process; ethnic differences in colorectal cancer; and a programme grant developing interventions to hasten earlier diagnosis.

We were delighted that so much of the work that was presented at the hugely successful NAEDI conference in March had connections with our subgroup.

4. Task groups/Working parties

Biomarkers workshop

The summary of the joint workshop held with the Biomarkers & Imaging CSG that was held in June 2014 was published in the autumn of 2014. However, impetus in taking this forward has been lost following the change in status of the B&I CSG into advisory groups. This will remain a priority for the group.

Screening

The Screening Subgroup is planning a research day to bring together the broader and multi-disciplinary cancer screening research community working at the primary care and public health interfaces with cancer screening, to share information on current research projects and potential future developments within cancer screening provision in the UK, and to map out a research agenda for cancer screening in the next 5-10 years. Participants include representatives of other NCRI CSGs (Breast, Colorectal, Gynaecology, Urology, Lung), the Department of Health's Policy Research Unit, policy leads across the UK's devolved health departments, and NHS and academic colleagues. We plan for leaders in the field to both provide the 'big picture' perspectives and to encourage discussion of future priorities. Discussion groups will be encouraged to explore together current evidence on reducing inequalities, concerns regarding over-diagnosis, informed uptake and communication of risk, the interface of screening and symptoms, and potential future screening modalities. Dr Campbell is in discussion with potential funders and speakers: we plan for a meeting in London in late 2015.

5. Patient recruitment summary for last 5 years

In the Primary Care CSG portfolio, 3 trials closed to recruitment and 1 opened.

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

Year	All subjects		Cancer patients	s only	% of cancer patients relative to incidence		
	Non-RCT	RCT	Non-RCT	RCT	Non-RCT	RCT	
2010/2011	2606	-	189	0	-	-	
2011/2012	5324	-	245	50	-	-	

Table 2 Summary of patient recruitment by Interventional/Non-interventional

Year	All participants		Cancer patient	s only	% of cancer patients relative to incidence		
	Non- Interventional		Non-	Non- Interventional		Interventional	
	interventional		interventional		interventional		
2012/2013	4543	0	64	0	-	-	
2013/2014	173	219	0	219	-	-	
2014/2015	829	1	709	1	-	-	

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

Members of the CSG were among a delegation of researchers who attended a joint meeting with senior Dutch primary care cancer researchers in Amsterdam in February 2015. At this meeting, future collaborations, and possible EU funding was discussed. The Dutch were also very keen to know why primary care cancer research in the UK has been so prolific and so successful in informing policy. The answer given was that it was primarily due to the NCRI Primary Care CSG in providing the framework and structure for collaboration.

Many members of the CSG and the wider primary care and cancer community contributed to the 8th annual Cancer and Primary Care International Research Network (Ca-PRI) conference in May in Aarhus. It is likely that applications for EU funding will emerge from this network.

Establishing excellent links with the network subspecialty leads is a priority for the forthcoming year.

7. Funding applications in last year

Table 3 Funding submissions in the reporting year

Other committees			
Study	Committee &	CI	Outcome
	application type		
Cancer: Life Affirming Survivorship support in	NIHR PGfAR /	Professor Paul	Pending
Primary care (CLASP) Programme	Programme	Little	
	Grant - Full		
	Proposal		
CARer-ADministration of as-needed sub-cutaneous	NIHR HTA /	Professor Clare	Pending
medication for breakthrough symptoms in	Project Grant -	Wilkinson	
homebased dying patients: a UK study (CARiAD)	Outline Proposal		
Noisy Breathing at Life's End. Is hyoscine	NIHR HTA /	Dr Marlise	Pending
hybromide more effective than placebo in	Project Grant -	Poolman	
managing family distress associated with Death	Outline Proposal		
Rattle. A randomised placebo-controlled trial.			
Lay referral in early diagnosis of cancer	Cancer Research	Dr Julia Hiscock	Unfunded
	Wales /		
	post-doc		
	fellowship		
Diagnostic journeys in Sarcoma	Sarcoma UK /	Professor Richard	Pending
	Project Grant -	Neal	
	Full Proposal		
Patient choice in prostate cancer hormone	Tenovus /	Professor Clare	Funded
treatment (Continuous androgen deprivation vs	PhD Studentship	Wilkinson	
intermittent androgen deprivation). (A CHOICe-PC)			
	NISCHR WG /	Professor Adrian	Funded
Wales Centre for Primary & Emergency Care	Project Grant -	Edwards	
Research (PRIME Centre Wales) (includes a work	Full Proposal		
package on prevention, screening and early			

diagnosis)			
Why do some smokers, and those diagnosed with lung cancer, delay, or avoid, presenting symptoms to their GP because of factors associated with smoking?	NISCHR / PhD Studentship	Professor Richard Neal	Funded
Lay referral in early diagnosis of cancer	Cancer Research UK post-doc fellowship	Dr Julia Hiscock	Unfunded
Cancer pathways to presentation and diagnosis.	MRC	Elka Humphreys? Fiona?	funded
Primary care suspected cancer referrals: understanding variation between practices and developing quality indicators	NIHR Doctoral Training Fellowship	Dr Thomas Round	Shortlisted
Weight loss as a predictor for cancer in primary care	NIHR Doctoral Training Fellowship	Dr Brian Nicholson	Shortlisted
Weight loss as a predictor for cancer in primary care	MRC Doctoral Training Fellowship	Dr Brian Nicholson	Shortlisted
Development of risk prediction models for breast, ovarian, prostate and other cancers	Cancer Research UK Programme Grant	Dr Antonis Antoniou	Pending
Survival from symptomatic ovarian and breast cancer in women in the UK: patient characteristics and symptoms reported in primary care linked to diagnosis and final outcome	Cancer Research UK post-doc fellowship	Dr Melanie Morris	Shortlisted
The CHEST trial: a randomized controlled trial to determine the clinical and cost-effectiveness of the CHEST intervention to reduce one-year mortality from lung cancer by prompting early consultation by people at high risk.	НТА	Dr Peter Murchie	Pending
Barrett's ESophagus Trial 3 (BEST3): Cluster randomised controlled trial comparing the Cytosponge-TFF3 test with usual care to facilitate the diagnosis of oesophageal pre-cancer in primary care	Cancer Research UK / Project Grant – Full Proposal	Prof Rebecca Fitzgerald / Dr Pierre Lao-Sirieix	Pending
What can we learn about how to improve uptake of bowel cancer screening from higher rates of uptake in breast and cervical screening programmes?	NAEDI / Project Grant - Full proposal	Dr Katie Robb	Funded
The role of health system interventions and government policy initiatives in promoting earlier diagnosis of cancer – what can we learn from the Detect Cancer Early programme in Scotland?	Scottish Government / PhD	Dr Christine Campbell	Funded
Understanding how 'lung cancer symptoms' and	Cancer Research		

'service': factors drive the decision to seek help	UK / Profect	Prof David Weller	Funded
from a GP in the Scottish public: a discrete choice	Grant - Full	& Dr Domenica	
experiment	proposal	Coxon	
IMPLICIT: IMPLementation of Cancer risk Tools in	National School	Dr Fiona Walter	Pending
primary care.	for Primary Care		
	Research		
BRACED: the BRAin Cancer Early Detection	The Brain	Dr Fiona Walter &	Pending
programme	Tumour Charity	Dr Alexis	
		Joannides	
BEYOND Cancer: Using Big Data to Identify	Sir Henry Dale	Dr Bhaskaran	Pending
Opportunities for Cardiovascular Disease	Fellowship,		
Prevention after Cancer	Wellcome Trust		
Ethnic differences in the use of primary care prior	Cancer Policy	Prof Willie	Pending
to prostate cancer diagnosis	Research Unit	Hamilton	
Acceptability of the Cytosponge test in preparation	CRUK	Prof Peter Sasieni	Successful
for the BEST3 trial: a qualitative study.	programme grant		
An integrated pathway for management and	Technology	Dr Alexis	Successful
monitoring of brain cancer	Strategy Board	Joannides	
What constitutes timeliness of diagnosis in general	NIHR In-practice	Dr Llanwarne	Successful
practice, and how do doctors' and patients' views	Fellowship		
differ on this? PI			
What is driving general practice variation in 'two-	NAEDI 3/ Cancer	Dr Yoryos	Successful
week wait' referrals and use of diagnostic tests,	Research UK	Lyratzopoulos	
and does it matter for cancer outcomes?			

8. Collaborative partnership studies with industry

The nature of our research means that we usually have few industry studies in the portfolio. However the ECASS trial that will open to recruitment soon, relies heavily on software provided by BMJ Informatica, and CLASP programme (awaiting final funding decision) also has close links with software suppliers. A study examining use of near patient testing of full blood count in patients having chemotherapy (funded, start date awaited) has been developed in collaboration with Philips.

9. Impact of CSG activities

Input into NICE Guidelines

At the time of writing, the update of the NICE 'Urgent Cancer Referral Guidance has not been published (although it is imminent). Hence it is difficult to speculate the impact of studies from the CSG on these guidelines. However, it is clear from the draft guidelines that were open to consultation late in 2014 that the impact of portfolio studies is hugely significant (as it should be).

Input into CR-UK Grand Challenge

Several members of the CSG participated in CR-UK Grand Challenge events. These events aimed to identify the really big research questions for the future – which will then be commissioned by Cancer Research UK

Input into developing the potential HTA themed call on risk assessment tools

Members of the CSG have been instrumental in persuading HTA to consider a themed call on risk assessment tools, and in commenting of the broad brief, prior to a final commissioning decision.

Input into Cancer Task Force (England)

Members of the CSG have contributed to this Task Force which will be reporting soon.

International conference presentation and participation

Members of the CSG have had a continued impactful contribution to a number of high-profile international conferences. These include: the NCRI conference where there was a survivorship symposium; the NAEDI conference which was dominated by studies that the CSG is / was closely connected to; and to two meetings of the International Cancer and Primary Care Research Network (Ca-PRI) (Winnipeg 2014, and Aarhus 2015). There was addition Ca-PRI badged meeting with researchers from the Netherlands that is likely to lead to development of an EU application (see International section). Lastly, the findings of the DISCOVERY programme (NIHR programme grant, led by Willie Hamilton) were presented at a one-day conference in June 2015 to an invited audience of clinicians, patients, commissioners, policy-makers, researchers, and the press.

10. Consumer involvement

Consumers are welcomed, supported and valued in the Primary Care CSG. They are working well with the health professionals in the group in a number of different ways. Consumers contribute to each of the subgroups – Early Diagnosis, Screening and Survivorship. The Screening Subgroup met in January 2015 which reviewed the role of the group. The Survivorship Subgroup reviewed and updated the group of its activities and portfolio in November 2014. These meetings give the consumers opportunities to get involved in the work of these groups. Mentoring of consumers is supported through their involvement with subgroup activities and also by their involvement in Advisory Group work for particular scientific studies, e.g. Talking about HPV related cancer: development and testing of scripted consultations has a Primary Care CSG consumer member as a member of its Advisory Group. The consumers have also given feedback on a research proposal, prior to submission for funding, by a Primary Care CSG GP. This gives the opportunity for Consumers to input thoughts and ideas relevant to patient concerns at the start of the research study and opportunities for the Consumers to be involved in the management group of the research study.

The consumers' learning and development is supported by the Consumer Liaison Group (Consumer Forum with effect from April 2015). This enables Consumers from all NCRI CSGs to share their experiences thereby providing for greater effectiveness and impact within the individual CSGs.

11. Open meetings/annual trials days/strategy days

In each previous annual report, we argued that for our CSG, holding an annual meeting is difficult because our vast number of 'constituents' in primary care, and because of our historic and ongoing lack of industry funded studies (hence difficulties in accessing funding sources). Hence we have always endeavoured to achieve the same result through a creative, multi-pronged approach to populating the 'best' fora for primary care oncology research (Ca-PRI, NAEDI, NCRI, SAPC), in the following manner. We achieved this through the following:

- Excellent contribution to CAPRI May 2015 (lead Professor David Weller, conference organiser)
- NAEDI workshop 2014 large representation from NCRI PCCSG
- Workshop for Liverpool NCRI 2014 meeting: Optimising care for those living with and beyond cancer where does primary care fit in? (Professor Watson, Dr Walter, Professor Wilkinson)

12. Progress towards achieving the CSG's 3 year strategy

There is no formal 3 year strategy in place. The previous strategy was set in 2011 and is no longer applicable. The general principles driving the work of the CSG have been increasing collaboration with other CSGs and emphasis on getting bigger studies and programmes of work onto the portfolio. We have made clear progress towards these as demonstrated elsewhere in this document. As previously mentioned, the CSG intend to hold a strategy day in November 2015 under the new Chair, Professor Neal.

13. Priorities and challenges for the forthcoming year

Priorities for the Primary Care CSG are:

- More studies being developed through the CSG. The CSG will prioritise the development of studies through the subgroups. The incoming chair intends to work closely with the subgroup chairs to find ways of working that will result in more studies being developed through the subgroups. Each of the subgroups are currently reviewing their membership and meeting structure. This work will inevitably involve working closely with other CSGs, consumer reps and other external agencies (see below). Each of the subgroups will be considering ways of developing studies that significantly increase accruals to portfolio studies (large trials and studies, and programme grants).
- Collaborative work with other CSGs. We intend to build on the good collaborative links we have with other CSGs already (Psychosocial Oncology & Survivorship, Supportive & Palliative Care, Skin, TYA, Lung and Colorectal), work on developing our emerging links with others (Prostate, Molecular Biomarkers Advisory Group), and develop links where they have previously not existed (for example in the harder to diagnose cancers upper GI cancers, brain, haematological).
- **Biomarkers.** We intend to take forward the scientific thinking and energy that was harnessed in the June 2014 Biomarkers workshop. This will need close engagement with the Moelcular Biomarkers Advisory Group, SPED, and several site-specific CSGs. We may consider seeking funding for a further Task Force or Working Group to take this agenda forwards.

Challenges for the Primary Care CSG are:

• **Portfolio.** The CSG continues to find it difficult to ensure that all of our studies are properly recorded and counted on the portfolio. Whilst we thought that we had previously solved this

difficult issue, it has become clear that there are enduring difficulties with this that need a long-term solution. Hence we will be working with the Secretariat to achieve this.

• Screening and Prevention. Prevention has been one area where the CSG has had few portfolio studies over the years. Working up prevention studies and getting them on the portfolio continues to be a challenge, although the CSG has begun some work to try and address this. We will cover this area at our Strategy Day in the autumn, and consider an application for a Task Force or Working Group to take this forwards. The subgroup is drafting a paper that seeks to outline the roles of primary care across the screening continuum, including facilitating discussion of screening with patients, supporting informed decision-making, follow-up of positive tests and support of screen-detected cancer as well as the interfaces of screening and symptomatic presentation and diagnosis in primary care. Dr Campbell is leading this work on behalf of the subgroup: it complements work led by Professor Weller, Dr Campbell and other colleagues describing the international landscape. A screening day is also planned for later in 2015.

NHS structures

The CSG has had some difficulty in fully engaging with new NHS structures and research networks. However, this is clearly of huge importance and the incoming chair will be working with the Secretariat on this. We also hope to appoint a new member to the CSG from the Clinical Research Network.

14. Concluding remarks

The CSG has been through a period of change, and will continue to do so until a number of new members are appointed and bedded in. The CSG has a Strategy Day in November 2015; this should identify a clear way forwards for the next three years.

15. Appendices

Appendix 1 - Membership of main CSG and subgroups

Appendix 2 – CSG and Subgroup strategies

A – Main CSG Strategy

B - Survivorship Subgroup Strategy

C - Screening Subgroup Strategy

D - Early Diagnosis Subgroup Strategy

Appendix 3 - Portfolio Maps

Appendix 4 - Publications in previous year

Appendix 5 - Major international presentations in previous year

Professor Clare Wilkinson (outgoing Primary Care CSG Chair) and Professor Richard Neal (incoming Primary Care CSG Chair)

Appendix 1

Membership of the Primary Care CSG

Name	Specialism	Location
Professor Eila Watson	Chair in Supportive Cancer Care	Oxford
Dr Nicola Thompson*	Clinical Fellow	Nottingham
Dr Brian Nicholson*	Clinical Fellow	Oxford
Dr Paul Brocklehurst	Clinician Scientist	Manchester
Mr Paul Charlton	Consumer	Felixstowe
Mrs Janice Rose	Consumer	Gloucester
Professor Richard Neal	General Practice	Bangor
Dr Fiona Walter	General Practice	Cambridge
Professor David Weller	General Practice	Edinburgh
Professor Clare Wilkinson (Chair)	General Practice	Bangor
Professor Nick Stuart	Medical Oncologist	Gwynedd
Dr Thomas Round	PCRN Rep	London
Professor Paul Little	Primary Care	Southampton
Dr Georgios Lyratzopoulos	Senior Clinical Research Associate	Cambridge
Dr Lucy Brindle	Senior Lecturer	Southampton
Dr Christine Campbell	Senior Research Fellow	Edinburgh
Dr Liz Mitchell	Senior Research Fellow	Leeds

^{*} denotes trainee

Membership of the Subgroups

Survivorship Subgroup								
Name	Specialism	Location						
Professor Eila Watson (Chair)	Chair in Supportive Cancer Care	Oxford						
Dr Fiona Walter	General Practice	Cambridge						
Professor David Weller	General Practice	Edinburgh						
Professor Clare Wilkinson	General Practice	Bangor						
Dr Jim Elliott	Head of Research, MacMillan	London						
Dr Lucy Brindle	Senior Lecturer	Southampton						
Dr Christine Campbell	Senior Research Fellow	Edinburgh						
Dr Gill Hubbard	Senior Research Fellow	Stirling						
Mr Peter Donnelly	Surgeon	Torbay						

Early Diagnosis Subgroup								
Name	Specialism	Location						
Mr Paul Charlton	Consumer	Felixstowe						
Professor Willie Hamilton	General Practice	Exeter						
Professor Richard Neal (Chair)	General Practice	Bangor						
Dr Fiona Walter	General Practice	Cambridge						
Professor Paul Little	Primary Care	Southampton						
Dr Peter Murchie	Primary Care	Aberdeen						
Professor Greg Rubin	Primary Care	Durham						
Mr Chris Hurt	Statistician	Cardiff						
Dr Yoryos Lyratzopoulos	Senior Clinical Research Associate	Cambridge						
Dr Suzanne Scott	Senior Lecturer	London						

Screening Subgroup										
Name	Specialism	Location								
Dr Paul Brocklehurt	Clinician Scientist	Manchester								
Professor Julietta Patnick	Director of the NHS Screening Programmes	Sheffield								
Professor Sue Moss	Epidemiologist	London								
Professor David Weller	General Practice	Edinburgh								
Professor Clare Wilkinson	General Practice	Bangor								
Professor Sheina Orbell	Psychologist	Essex								
Ms Alison Clements	Qualitative Researcher	Oxford								
Dr Georgios Lyratzopoulos	Senior Clinical Research Associate	Cambridge								
Dr Christine Campbell (Chair)	Senior Research Fellow	Edinburgh								
Mr Chris Hurt	Statistician	Cardiff								

Appendix 2

CSG & Subgroup Strategies

A - Main CSG Strategy

Please see comments in section 12.

B - Survivorship Subgroup Strategy

Overall strategy: To conduct high quality research to further understand and promote the role of primary care in relation to optimising the health and well-being of cancer survivors

Short term goals:

- To continue to support studies within the portfolio
- To foster links with other CSGs, and identify opportunities for collaborating on the development of high quality studies
- To secure funding for two areas of work with fully developed proposals: promoting healthy lifestyles and wellbeing in cancer survivors in primary care; supporting adherence to adjuvant endocrine therapy in women with breast cancer

Medium/longer term goals:

- To continue to increase the number of high quality portfolio studies
- To build on prostate pilot trials and
- secure funding for a large, multi-centre Phase III trial
- trial different approaches to follow-up in other cancers e.g. colorectal, testicular
- To develop research proposals focussing on supporting patients with symptom appraisal following completion of initial cancer treatment, and the role of primary care in detecting recurrence and supporting patients who experience a recurrence.

C - Screening Subgroup Strategy

Overall aim: to carry out high quality research to provide a methodologically sound and policy relevant evidence base to develop and promote the role of primary care in cancer screening

Short-term goals:

- To continue to support funded studies within the Portfolio
- To continue to foster links with other CSGs, particularly colorectal, breast, gynae and lung, in the development of high quality studies and trials, and with a focus in SPED priority areas.
- To continue to review the current screening research portfolio within the UK, identifying strengths and weakness with respect to supporting patients, the screening programmes, and primary care
- To hold a UK-wide 'Primary Care and Cancer Screening' research day in autumn/ winter of 2015
- To secure funding for an oral cancer case-detection/screening feasibility study
- To secure funding for a comparative review of screening policies across the devolved nations
 of the UK

Medium/longer term goals:

- To continue to increase the number of high quality portfolio studies, the number of general practices engaged in this research, and patients enrolled in portfolio studies. Examples under discussion include:
- Examining the impact of current policy initiatives on screening uptake and outcomes
- Intervention studies to address low up-take of screening in ethnic minority and immigrant communities
- Examine the interfaces of screening and symptomatic presentation in primary care
- To identify opportunities with international primary care and screening colleagues (e.g. Ca-PRI, and the International Cancer Screening Network) for collaborative comparative effectiveness research.

D - Early Diagnosis Subgroup Strategy

Overall strategy: To conduct high quality research to achieve earlier diagnosis of cancer through primary care.

Short/Medium term goals:

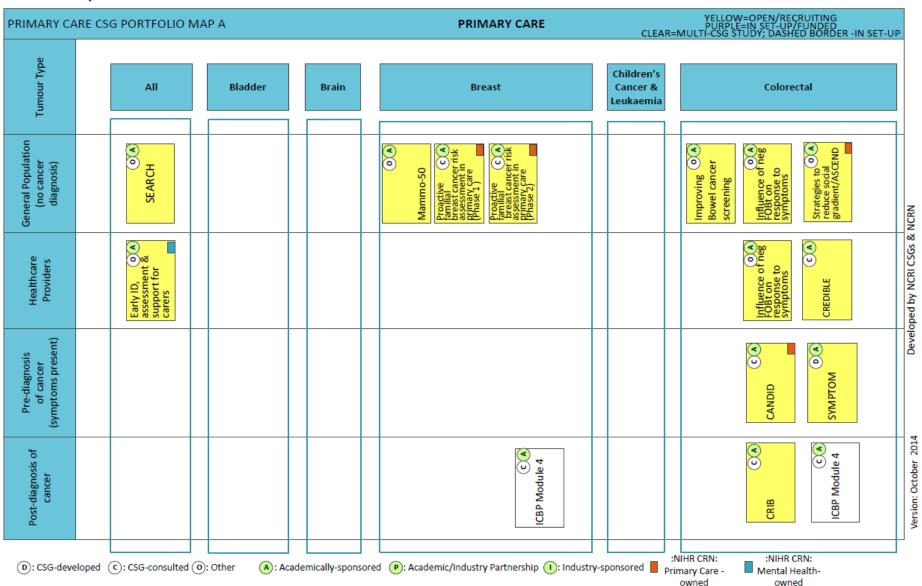
- To continue to support funded studies within the current portfolio
- To work closely with other CSG in the development of studies
- To develop work with the Molecular Biomarkers Advisory Group
- To work closely with SPED ensuring a robust primary care input. 'Primary care' is one of the three key themes of SPED's work

Longer term goals:

- To continue to secure an increasing trajectory of high quality studies to the portfolio, and an increasing trajectory of accrued patients
- To see the output from portfolio studies being translated into timelier diagnosis and better patient outcomes
- To secure funding for the innovative trials of biomarkers in primary care settings

Appendix 3

Portfolio maps



PRIMARY C	ARE CSG PORTFOLIO MA	AP B		PRIMARY CARE	YELLOW=OPEN/RECRUITING PURPLE=IN SET-UP/FUNDED EAR=MULTI-CSG STUDY; DASHED BORDER -IN SET-UP
Tumour Type	Gynae	Haem Onc	Head & Neck	Lung	Lymphoma Melanoma
General Population (no cancer diagnosis)	Self-sampled HPV testing for cervial screening non-responders v 1.0			Liverpool Lung Project SEARCH	
Healthcare Providers					
Pre-diagnosis of cancer (symptoms present)				CANDID SYMPTOM	
Post-diagnosis of cancer	ICBP Module 4			ICBP Module 4	
	(D): CSG-developed (C): CSG-consulted ①: Oth	er (A): Academical	ly-sponsored P: Academic/Industry Partnership 1:	:NIHR CRN: Industry-sponsored Primary Care owned

PRIMARY CA	PRIMARY CARE CSG PORTFOLIO MAP C			I	PRIMARY CARE			YELLOW=OPEN/RECRUITING PURPLE=IN SET-UP/FUNDED CLEAR=MULTI-CSG STUDY; DASHED BORDER -IN SET-UP					
Tumour Type		Prostate		Renal		Sarcoma		Teenage & Young Adults		Testis		Upper GI	
General Population (no cancer diagnosis)													RN
Healthcare Providers													Developed by NCRI CSGs & NCRN
Pre-diagnosis of cancer (symptoms present)												SYMPTOM	Develor
Post-diagnosis of cancer													Version: October 2014
		D: CSG-develop	ped ©:CSC	G-consulted (0): Oth	ner (A):	Academically-spon	sored P: A	cademic/Industry Pa	artnership	1): Industry-spon	sored	:NIHR CRN: Primary Care- owned	

Appendix 4

Publications in the reporting year

DISCOVERY programme/SYMPTOM study:

Walter FM, Rubin G, Bankhead C, Morris HC, Hall N, Mills K, Dobson C, Rintoul R, Hamilton W, Emery J. First symptoms and other factors associated with time to presentation and diagnosis and stage at diagnosis of lung cancer: a prospective cohort study. *Brit J Cancer*. 2015 Mar 31;112 Suppl:S6-S13. doi: 10.1038/bjc.2015.30. PMID: 25734397.

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Mammo-50 Trial

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TOPCAT-P Trial

Stanciu MA, Morris C, Makin M, Watson E, Bulger J, Evans R, Hiscock J, Hoare Z, Tudor Edwards R, Neal RD, Wilkinson C. pilot randomised controlled trial of personalised care after treatment for prostate cancer (TOPCAT-P): nurse-led holistic-needs assessment and individualised psychoeducational intervention: study protocol. *MJ Open* 2015;5:e008470 doi:10.1136/bmjopen-2015-008470

Appendix 5

Major international presentations in the reporting year

DISCOVERY programme/SYMPTOM study

Jun 2014: 7th CaPRI annual meeting, Winnipeg, Canada.

Jun 2014: National Cancer Registry Service, Cambridge.

July 2014: SAPC annual meeting, Edinburgh.

MELANOMA INTERVIEW study

Dec 2014: UICC- World Cancer Congress, Melbourne, Australia.

MELATOOLS programme

Oct 2014: Cancer Policy Research Unit, Queen Marys, University London.

Dec 2014: UICC- World Cancer Congress, Melbourne, Australia.

ELCID

Neal RD, on behalf of the ELCID trial team. A feasibility randomised controlled trial looking at the effect on lung cancer diagnosis of giving a Chest X-Ray to smokers aged over 60 with new chest symptoms – feasibility and two-month follow-up data. Ca-PRI, Aarhus, May 2015.

Neal RD, on behalf of the ELCID trial team. A feasibility randomised controlled trial looking at the effect on lung cancer diagnosis of giving a Chest X-Ray to smokers aged over 60 with new chest symptoms – feasibility and two-month follow-up data. NAEDI Research Conference, London, March 2015.

Neal RD, on behalf of the ELCID trial team. A feasibility randomised controlled trial looking at the effect on lung cancer diagnosis of giving a Chest X-Ray to smokers aged over 60 with new chest symptoms – feasibility and two-month follow-up data. South West SAPC Birmingham January 2015.

Neal RD, on behalf of the ELCID trial team. A feasibility randomised controlled trial looking at the effect on lung cancer diagnosis of giving a Chest X-Ray to smokers aged over 60 with new chest symptoms - the ELCID trial. SAPC Annual Scientific Meeting, Edinburgh July 2014

Identification and support of carers of people approaching end of life

Carduff E. European Association of Palliative Care, Copenhagen. Piloting a new approach to identifying, assessing and supporting carers of people with palliative care needs in primary care. oral presentation). 2015.

Carduff E. Piloting a new approach to identifying, assessing and supporting carers of people with palliative care needs in primary care Carduff E, Highet G, Finucane A, Kendall M, Jarvis A,

Harrison N, Greenacre J, Murray S, BMJ Support Palliat Care. 2015 Mar;5(1):115. doi: 10.1136/bmjspcare-2014-000838.34. (oral presentation)

The influence of a negative FOBt on the response of screening invitees and healthcare providers to symptoms of colorectal cancer

Campbell C. NAEDI conference, London. The influence of a negative screening test result on response to symptoms among participants of bowel cancer screening programmes. March 2015.

ASCEND study

Smith S. Examining the effect of a 'gist-based' colorectal cancer screening information leaflet: A multi-centre parallel randomised controlled trial. (Presentation) Society for Behavioural Medicine, Philadelphia, April 2014. *Awarded "Meritous Student Abstract"*

Von Wagner C. Decision-making and participation in bowel cancer screening: Challenges and interventions for low health literate individuals (Symposium). (Presentation) 12th International Conference on Communication in Healthcare, Amsterdam, The Netherlands, September, 2014.