

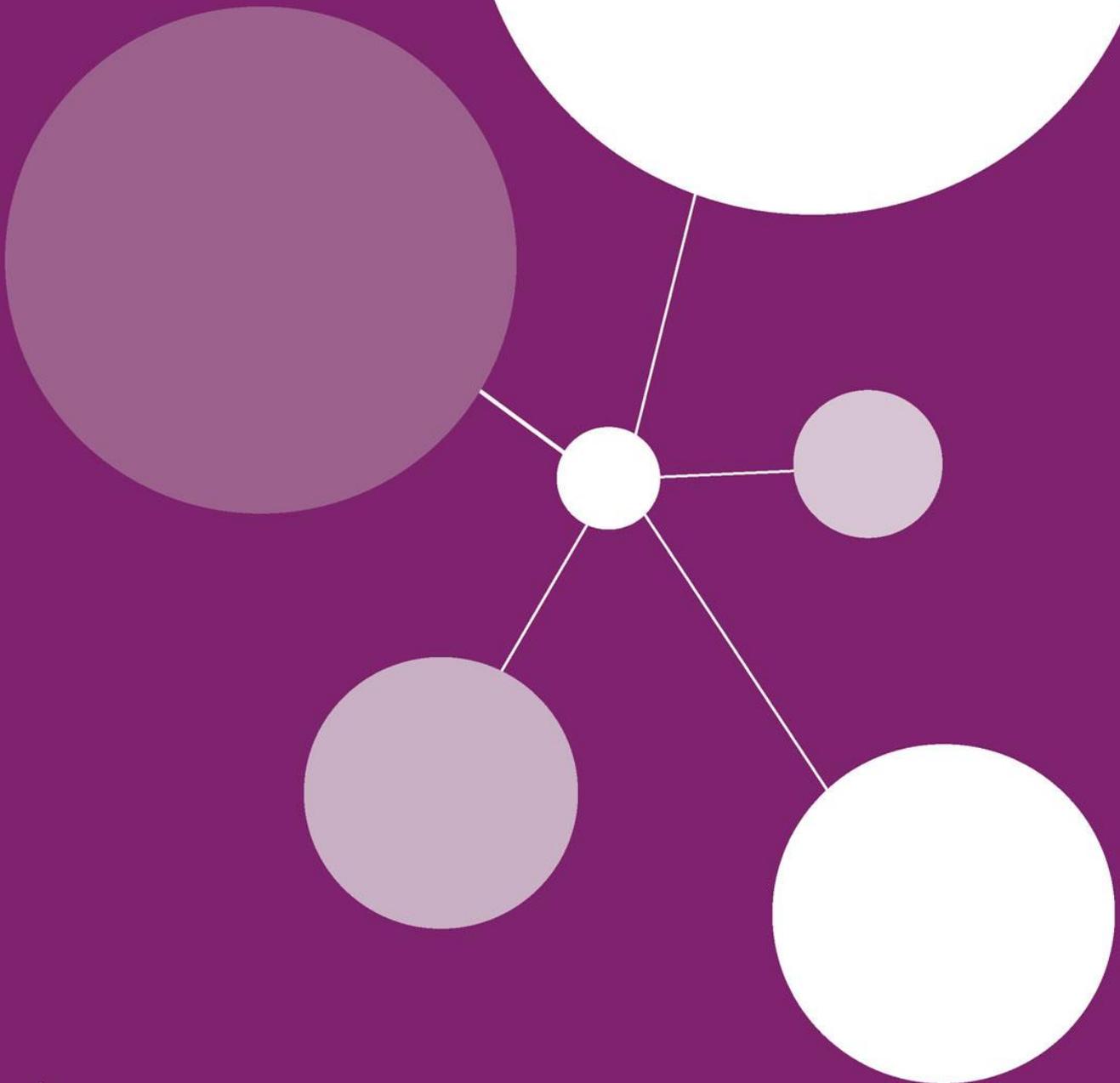


NCRI

National
Cancer
Research
Institute

NCRI Primary Care Clinical Studies Group

Annual Report 2015-16



Partners in cancer research



NCRI Primary Care CSG Annual Report 2015-16

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

It has been both an exciting and challenging year for the Primary Care CSG. It has been my first year as Chair, and this year has included both a Quinquennial Review (QQR) and a Strategy Day. I envisage that, over the coming years, our new Strategy (to take effect from October 2016) will stand us in good stead to continue our goals of increasing the number, quality and breadth of studies on/across the portfolio, increasing the number of accruals to portfolio studies, and increasing the size and expertise of the primary care cancer research community. The three top achievements in the year are:

1. A successful QQR and using this to inform the Strategy Day: As a CSG we were delighted with the outcome of our QQR panel (see Appendix 6 for full details). These conclusions were taken forward to our Strategy Day, discussed in full, and will contribute to our final Strategy document that we will approve in the autumn. We are very grateful to Macmillan Cancer Support for providing financial support for our Strategy Day (getting industrial / pharmaceutical support is very difficult for us).
2. A significant increase in accruals to portfolio studies: We are delighted about the very significant increase in the number of accruals for 2015-16 (see Section 5). This is the result of much hard work over many years. We envisage that this upward trajectory will continue.
3. Continued upward trajectory of successful portfolio studies and large grant funding applications: Over the year two programme grants have been funded (CLASP and WICKED), and the portfolio is increasing in size and scope. We have also increased our ambition. CSG members have led two applications that are through to the final round for the Cancer Research UK CATALYST award.

2. Structure of the Group

The overall structure of the Subgroups has remained the same. Over the past year we have welcomed new members to the CSG – Rhian Gabe, Peter Murchie, Una Macleod, Sunil Dolwani and Katriina Whitaker. The range of disciplines that they represent will stand us in good stead. I would like to thank Yoryos Lyratzopoulos who has rotated off the Group, and in particular Clare Wilkinson, who has stepped down after two successful terms as Chair. I would also like to thank our two outgoing trainees – Brian Nicholson and Nicola Thompson.

3. CSG & Subgroup strategies

Main CSG

The CSG held its Strategy Day on 19 May 2016, thanks to welcome financial support from Macmillan Cancer Support. The Day was facilitated by Professor Greg Rubin, and attended by CSG members and a number of external guests and speakers. This was the CSG's first Strategy Day for a number of years, and some very useful work was undertaken during the day. A report will be forthcoming, alongside a draft strategy that will emerge. This draft strategy will then be revised within the subgroups and a final strategy will be presented to the meeting of the main CSG in October for sign-off. Whilst it is impossible to go into any detail here regarding the strategy, we have not had a Strategy Day for some time and this gave us a welcome opportunity to more formally think strategically about future directions of our portfolio. This may sound both self-evident and rather naïve, but clearly demonstrate that the Strategy Day has been exceptionally useful in our forward planning.

Survivorship Subgroup (Chair, Professor Eila Watson)

The previous strategy is included in the Appendix; the new Strategy will take effect from October 2016. Key strategic aims that have been achieved during the previous year include:

1. Funding of an NIHR Program Grant – Cancer Life-Affirming Support in Primary Care (CLASP) which aims to promote healthy lifestyles and well-being in cancer survivors in primary care.
2. We await the outcome of two proposals developed in collaboration with the Psychosocial Oncology & Survivorship CSG:
 - A proposal to test the feasibility of a community pharmacy intervention to support breast cancer survivors with adherence to adjuvant endocrine therapy, submitted to Breast Cancer Now.
 - A proposal exploring symptom appraisal and pathways to a diagnosis of recurrence in women with breast cancer, submitted to NIHR Research for Patient Benefit.
3. We are currently developing collaborative proposals with the Testicular Cancer, Haematological and Skin Cancer CSGs.
4. We have recruited a community nurse to the Subgroup.

Screening Subgroup (Chair, Dr Christine Campbell)

The previous strategy is included in the Appendix. The new Strategy will take effect from October 2016. Key strategic aims that have been achieved during the previous year include:

1. Refreshing the membership of the Subgroup over the last year to include a health psychologist with expertise in cancer screening, a clinical trial statistician and an additional epidemiologist:
Following the retirement of Professor Julietta Patnick we have recruited Anne Stevenson from PHE Screening.
2. Holding a Primary Care and Cancer Screening Research Day on 7 March 2016:
Approximately 80 delegates from across the UK attended, including from other NCRI CSGs and NCRI consumers, representatives of screening programmes, government health departments, and academic colleagues from different disciplines and institutions. Discussions from the Research Day are being integrated with outcomes of the May CSG Strategy Day to provide a framework for engagement with Breast, Gynaecological, Colorectal and Lung CSGs and the development of novel funding applications. It is likely these will focus in the areas of the ongoing need to address inequalities in screening

participation, over-diagnosis, informed uptake and risk communication, the potential introduction of lung cancer screening in the UK, and exploring stratified approaches to screening that incorporate genetic risk and family history.

Early Diagnosis Subgroup (Chair, Dr Fiona Walter)

The previous strategy is included in the Appendix. The new strategy will take effect from October 2016. Key strategic aims that have been achieved during the previous year include:

1. Revising the Subgroup membership to include social scientists and a lay member.
2. Completing the flagship NIHR funded Discovery programme (CI – W Hamilton) which has led to: publication of 20 peer-reviewed papers; completion of four PhDs; use of findings to underpin much of the 2015 revision of NICE guidance on investigation of cancer; and use of findings to catalyse Department of Health efforts to improve UK cancer diagnosis with the ACE programme.

4. Task groups/Working parties

The Primary Care CSG has no task groups or working parties.

5. Patient recruitment summary for last 5 years

In the Primary Care CSG portfolio, 3 trials closed to recruitment and 2 opened.

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

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

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	4543	0	64	0	-	-
2013/2014	173	219	0	219	-	-
2014/2015	829	1	709	1	-	-
2015/2016	27657	2412	6915	2391	-	-

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

The Primary Care CSG has a number of links with other groups, including:

- CSGs: We have links with many of the site specific CSGs. These have led to funded studies in collaboration with the Prostate, Lung, Brain, Upper GI and Skin Cancer CSGs, and applications submitted with members of the Sarcoma, Head & Neck and Psychosocial Oncology & Survivorship CSGs. We are developing links with other CSGs. However, there is a risk of our resources becoming overstretched (see Section 12). Three Primary Care CSG members sit on the Screening, Prevention & Early Diagnosis (SPED)

Advisory Group; this has been very useful for developing proposals with other CSGs (e.g. Prostate, Head & Neck), and we look forward to this continuing into the future.

- International Groups: CSG members have made significant contributions to the International Cancer Benchmarking Partnership (ICBP). Further work is being developed. Many members work closely with Ca-PRI (Cancer and Primary Care International Research Network). The two CATALYST award applications have significant international input.
- Network Speciality Leads: We have liaised with Professor Sam Ahmedzai (National Speciality Lead) and will continue to do so, and with Dr Tony Crockett (Specialty Lead Primary Care), who contributed to our Strategy Day.

7. Funding applications in last year

Table 3 Funding submissions in the reporting year

Cancer Research UK Clinical Research Committee (CRUK CRC)			
Study	Application type	CI	Outcome
July 2015 (CTAAC)			
None			
May 2016			
CANDID: CANcer Diagnosis Decision rules		Professor Christian Ottensmeier & Professor Paul Little	Not funded
Other committees			
Study	Committee & application type	CI	Outcome
Development and evaluation of eCHEST: A self-directed digital intervention to support earlier presentation of significant chest symptoms by those at risk of serious lung disease	Scottish Government Chief Scientist Office and British Lung Foundation	Dr Peter Murchie	Not funded by either
CLASP: Cancer Life Affirming Support in Primary Care	NIHR PGfAR	Professor Paul Little	Funded
ASICA: Achieving Self-directed Integrated Cancer Aftercare in melanoma: A randomized patient-focused trial of delivering the ASICA intervention as a means to earlier detection of second primary melanomas	Cancer Research UK	Dr Peter Murchie	Funded
CRIB 2: A pragmatic, multi-centre randomised controlled trial to compare the clinical and cost-effectiveness of cardiac rehabilitation vs. usual care (no rehabilitation) on colorectal cancer patients' physical activity and sedentary behaviour, quality of life, fatigue and 5 year survival	NIHR HSDR	Dr Gill Hubbard	Not funded
Improving adherence to adjuvant endocrine therapy in women with breast cancer: a feasibility trial of a community pharmacy intervention	NIHR HSDR and Breast Cancer Now	Professor Eila Watson	Not funded by HSDR, outcome awaited from Breast Cancer Now

Symptom appraisal following primary breast cancer: promoting timely presentation to health services with possible symptoms of recurrence.	Breast Cancer Now and Research for Patient Benefit	Professor Eila Watson	Not funded by BCN, outcome awaited from RfPB
Second primary cancers: a mixed-methods study to understand pathways to diagnosis, patient and provider experiences, and survival outcomes	Cancer Research UK	Dr Christine Campbell	Funded
A CHOICe-PC: Androgens - CHOice of Intermittent vs Continual- Prostate Cancer	Tenovus	Professor Clare Wilkinson & Professor Richard Neal	Funded
CARiAD: CARer-ADministration of as-needed subcutaneous medication for breakthrough symptoms in home based dying patients: a UK study	HTA	Professor Clare Wilkinson	Funded
WICKED (Wales Interventions and Cancer Knowledge about Early Diagnosis): The development and evaluation of primary care interventions to expedite the diagnosis of symptomatic cancer in Wales	Cancer Research Wales	Professor Richard Neal	Funded
Empowering high risk, harder to reach groups to engage with lung cancer awareness and timely symptom presentation.	Cancer Research UK	Dr Kate Brain	Funded
Efficacy and utility of the new Cancer Research UK oral cancer educational programme in improving the case detection of oral cancer amongst General Practitioners: a mixed methods approach using a parallel experimental design and semi-structured interviews	Cancer Research UK	Professor Paul Brocklehurst	Not funded
DJiP: Diagnostic journeys in prostate cancer	Cancer Research Wales	Professor Richard Neal	Awaited
Diagnostic journeys in sarcomas	Sarcoma UK	Professor Richard Neal	Awaited
CanTest: Detecting cancer in primary care: a paradigm shift cancer diagnosis.	CR-UK Catalyst award	Dr Fiona Walter & Professor Willie Hamilton	Awaited
Title3D: An international network in cancer prevention, early diagnosis and screening	CR-UK Catalyst award	Professor David Weller	Awaited
ABACus (Awareness and Beliefs About Cancer): randomised controlled trial of the health check intervention to improve cancer symptom awareness and help seeking among people living in socioeconomically deprived communities	Yorkshire Cancer Research	Dr Kate Brain	Awaited
Yorkshire Lung Screening Trial	Yorkshire Cancer Research	Dr Mat Callister	Awaited
Cytology as triage test to detect cervical cancer in women with gynaecological symptoms	Yorkshire Cancer Research	Dr Anita Lim	Awaited

8. Collaborative partnership studies with industry

As with previous years, we have relatively few links with industry. However, the ECASS trial (now open) uses software supplied by BMJ Informatica, the MelaTools I study is investigating GP behaviour using software integrated by EMIS Web, and the CLASP programme also has close links with software suppliers.

9. Impact of CSG activities

Many of the CSG's outputs informed NICE Guideline NG12 (Suspected cancer: recognition and referral) which was published last year, most notably the series of papers from the DISCOVERY NIHR programme.

Members of the CSG provided input into the Cancer Task Force (England) which reported in the past year and is being hugely influential in shaping cancer services into the future. Some members also contributed to the influential Lancet Oncology commission: 'The expanding role of primary care in cancer control' (Rubin et al. Lancet Oncol. 2015;16(12):1231-72).

Our work has been widely disseminated at international and national conferences, including NCRI, SAPC, NCIN, NAEDI, NAPCRG, Ca-PRI, and BPOS.

Many of our members contribute to Governmental and Charitable Funding Boards including (amongst others) NIHR, Cancer Research UK, Roy Castle Lung Cancer Foundation, Yorkshire Cancer Research, Target Ovarian Cancer, Prostate Cancer UK, Tenovus Cancer Care.

10. Consumer involvement

Janice Rose

The past year has been my second year with the Primary Care CSG. My involvement with the Group, and the Screening and Survivorship Subgroups in particular, has grown throughout the year.

The following summarises my activities this year:

- The Screening and Survivorship Subgroups have held face-to-face meetings to discuss research going forward which I attended. Felt welcomed and an equal member.
- Screening Research Day held March 2016 - included a wider group of researchers and patients than that of the sub-group. An informative and educational day for me.
- I am a Consumer Member of the Research Advisory Group for the project 'Talking about HPV related Cancer'. A paper was published in February 2016. Communication has worked well between myself and the researchers.
- Working with researchers in the Survivorship Subgroup, I am co-applicant for a project proposal looking at appraisal of symptoms for patients with recurrence of breast cancer. I have been involved from the outset of the project.
- Attended the launch of the DISCOVERY Research Programme in June 2015. This work was part of the Early Diagnosis Subgroup work.
- WICKED (Wales Interventions and Cancer Knowledge about Early Diagnosis) is a new project on the CSG's portfolio. I have agreed to be a patient representative on the Research Advisory Group for this research.
- Attended the NCRI Cancer Conference in 2015 for the first time. This supported my knowledge and development as a Consumer Member very well.
- The support provided by the Consumer Forum to Consumer Members in Clinical Studies Groups is invaluable. Regular weekly updates of what is happening in the field of cancer research and how patients and the public can be involved and support this are sent out. The group of Consumer Members is a useful group to work with. I shared the results with the Primary Care Clinical Studies Group, the report of work carried out by Consumer Members about the National Cancer Patient Experience Survey results.

- During this last year the Primary Care Clinical Studies Group was subject to a Quinquennial Review. Consumer members were asked to write and submit their experiences over the period 2011-2015. The review and its findings were included in the Strategy Day (19 May 2016) for the CSG. Interesting discussions on this day will form the basis for future work of the group in the next 3 - 5 years.

Professor Eila Watson, Chair of the Survivorship Subgroup, is my mentor. I have found it useful working alongside her contributing as a co-applicant for one of her funding applications. It has been a useful way of getting to know her.

Building on from what has been achieved this year, I am looking forward to continuing to work with the members of the Primary CSG in the year ahead.

Ann Russell

I was a member of the Colorectal CSG until September 2015. From October I have been a member of the Primary Care CSG. I continue my involvement with the Colorectal CSG by invitation of the Chairs of the Surgery and Adjuvant & Advanced Disease Subgroups. I am not yet a member of any Primary Care CSG Subgroup. I am a member of the following:

- TMGs
 - TREC – Transanal Endoscopic Microsurgery and Radiotherapy in Early Rectal Cancer. A phase 11 interventional trial sponsored by the trials unit at University of Birmingham.
 - STAR-TREC Saving the Rectum by watchful waiting or Transanal surgery after (chemo) Radiotherapy versus Total mesorectal excision for Early Rectal Cancer. A randomised Phase II feasibility study sponsored by the trials unit at University of Birmingham.
- TSGs
 - FOCUS4 – A randomised controlled trial of dabrafenib, trametinib and panitumumab versus dabrafenib and panitumumab alone versus placebo in patients with BRAF mutant, advanced colorectal cancer that is stable or responding after first line chemotherapy. Sponsored by MRC.
 - ADD ASPIRIN – A phase 111 double blind placebo randomised trial assessing the addition of aspirin after standard primary therapy in early stage common solid tumours. Sponsored by University College, London.
 - CHALLENGE-UK UK arm of Colon Health and Lifelong Exercise change trial – set up in Canada/Australia. Sponsored by University of Belfast.
- TDGs
 - BORODIN – A randomised feasibility study of biological mesh reinforcement during closure of complex and contaminated abdominal wall incision. Sponsored by University of Birmingham.
 - Nutrition and Cancer NIHR Infrastructure Collaboration NIHR Southampton Biomedical Research Council, World Cancer Research Fund UK sponsored by the NIHR.
 - TXT-NETTING project – text messages to cancer patients reminding them of medication routines, appointment dates, etc sponsored by Centre for Cancer Prevention, Queen May University London
 - Manuscript Co-author - Trial outcomes and information for clinical decision-making: a comparative study of opinions of health professionals. Sponsored by Bristol University.

- Locally
 - Member of CUH Addenbrookes CPPG; Cambridge Breast Unit Research Group at CUH CRUK Cambridge Institute and CUH Cancer Strategy Steering Group.
- Regionally
 - Patient rep - CRN-Eastern.
 - Recently recruited by MRC-CTU as one of two patients on newly developed overarching cancer TSC created to oversee all their cancer trials replacing all their individual TSC's.

I have two scientific mentors: Mr Simon Bach (Colorectal involvement) and Dr Fiona Walter (Primary Care CSG).

11. Open meetings/annual trials days/strategy days

Please refer to Section 3 for an update regarding our successful Strategy Day.

To date, the CSG has never held an Annual Trials Meeting. There are many reasons for this, which have been well documented in the past. However there are now possibilities for running a Trials Meeting as a satellite session at the RCGP Annual Conference, possibly in conjunction with a regional cancer charity. The CSG is currently working on these plans and are hopeful of holding its first Trials Meeting within the next two years.

12. Priorities and challenges for the forthcoming year

Priorities for the Primary Care CSG are to:

1. Finalise and approve the new Strategy and develop processes to deliver on this Strategy. Completion of this will undertake our work plan for the coming years. This is a key activity for us over the summer months. We collected a lot of material on the Strategy Day (presentations regarding our wider context and environment, funding priorities, 'homework' (strengths, weaknesses, threats, and opportunities), outputs from small group work, and outputs from our subsequent discussions. We will work on this over the summer and develop the Strategy for sign-off at the October meeting.
2. Make progress on holding the CSG's first Annual Trials Meeting. As mentioned in Section 11 above, the CSG has never managed to hold a Trials Meeting. Although still a challenge to do so, some progress has been made to do so in the future. We aim to build on this progress with the aim of holding our first Trials Meeting within the next two years.
3. Continue to oversee an increase in the number of successful grant applications through the CSG and to be increasingly ambitious in these. All the metrics that demonstrate the value and impact of the CSG are going in the right direction (number of portfolio studies, success rate of funding, number of patients accrued, participation of a greater number of members and Subgroup members). Our priority is to ensure that this remains the case over the next year, and subsequent years. Finalising and operationalising our new Strategy is fundamental to achieving this.

Challenges for the Primary Care CSG are:

1. Portfolio: Whilst significant progress has been made since last year's Annual Report, we continue to have some concerns that the Portfolio does not properly reflect our activity. We are working to find a way of ensuring that studies led by the DH Policy Research Unit

on Screening Awareness and Early Diagnosis are captured on the Portfolio. Issues relating to the Portfolio also appeared in the recommendations of the QQR.

2. Biomarkers: Developing collaborations with the biomarker community has been one of our priorities for some time but we have not made as much progress on this as we would have envisaged, despite a well-attended and useful combined study day in 2014. It has proved to be a challenge for a number of reasons, including changing structures within NCRI. Over the coming year we will seek ways of overcoming some of the difficulties that we have had and continue to prioritise the development of work in this area.
3. Collaborative work with other CSGs: Over the past several years, we have prioritised the development of work with other CSGs, and this has been relatively successful. The challenge that we now face is that we are getting overstretched in terms of expanding both the volume and scope of our work with other CSGs. This is something that was discussed in both the QQR and the Strategy Day, and ways of rising to this challenge will form part of our ongoing strategy.

13. 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

Appendix 6 – Strengths & Weaknesses from the Primary Care CSG 2016 Progress Review

Professor Richard Neal (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 Sunil Dolwani	Clinical Lecturer	Cardiff
Dr Paul Brocklehurst	Clinician Scientist	Manchester
Mrs Janice Rose	Consumer	Gloucester
Mrs Ann Russell	Consumer	St Neots
Professor Una Macleod	General Practice	Glasgow
Professor Richard Neal (Chair)	General Practice	Bangor
Dr Fiona Walter	General Practice	Cambridge
Professor David Weller	General Practice	Edinburgh
Dr Thomas Round	PCRN Rep	London
Professor Paul Little	Primary Care	Southampton
Dr Katriina Whitaker	Senior Lecturer and Lead in Cancer Care	Guilford
Dr Lucy Brindle	Senior Lecturer	Southampton
Dr Sunil Dolwani	Senior Lecturer	Cardiff
Dr Peter Murchie	Senior Lecturer	Aberdeen
Dr Katriina Whitaker	Senior Lecturer	Guilford
Dr Christine Campbell	Senior Research Fellow	Edinburgh
Dr Liz Mitchell	Senior Research Fellow	Leeds
Dr Rhian Gabe	Statistician	London

*denotes trainee member

Membership of the Subgroups

Survivorship Subgroup		
Name	Specialism	Location
Professor Eila Watson (Chair)	Chair in Supportive Cancer Care	Oxford
Dr Nicola Thompson*	Clinical Fellow	Nottingham
Dr Brian Nicholson*	Clinical Fellow	Oxford
Mrs Janice Rose	Consumer	Gloucester
Dr Fiona Walter	General Practice	Cambridge
Professor David Weller	General Practice	Edinburgh
Dr Jim Elliott	Research Consultant, Consumer Advocate	London
Dr Beth Hardy	Lecturer	York
Dr Lucy Brindle	Associate Professor	Southampton
Dr Peter Murchie	Senior Lecturer	Aberdeen
Dr Nicola Gray	Senior Lecturer	Dundee
Dr Gill Hubbard	Reader	Stirling
Mr Peter Donnelly**	Surgeon	Torbay

Early Diagnosis Subgroup		
Name	Specialism	Location
Dr Brian Nicholson*	Clinical Fellow	Oxford
Mrs Margaret Johnson	Consumer	Cambridge
Professor Willie Hamilton	General Practice	Exeter
Professor Richard Neal	General Practice	Bangor
Dr Fiona Walter (Chair)	General Practice	Cambridge
Professor Paul Little	Primary Care	Southampton
Dr Peter Murchie	Primary Care	Aberdeen
Professor Greg Rubin	Primary Care	Durham
Dr Yoryos Lyratzopoulos	Senior Clinical Research Associate	Cambridge
Dr Suzanne Scott	Senior Lecturer	London
Dr Katriina Whittaker	Senior Lecturer	Guilford

Screening Subgroup		
Name	Specialism	Location
Dr Paul Brocklehurst	Clinician Scientist	Manchester
Mrs Janice Rose	Consumer	Gloucester
Professor Sue Moss	Epidemiologist	London
Professor David Weller	General Practice	Edinburgh
Professor Clare Wilkinson	General Practice	Bangor
Mrs Anne Stevenson	National Programmes Lead, PHE Screening	Gloucester
Dr Jo Waller	Principal Research Psychologist	London
Professor Sheina Orbell	Psychologist	Essex
Dr Christine Campbell (Chair)	Senior Research Fellow	Edinburgh
Dr Rhian Gabe	Statistician	London
Dr Anita Lim	Senior Epidemiologist	London

*denotes trainee member **denotes non-core member

Appendix 2

CSG & Subgroup Strategies

A – Main CSG Strategy

The strategy is under review and the strategy document is currently being written up following the recent strategy day, this will be finalised by the Group at our October CSG meeting. 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.

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 111 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, Gynaecological 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 CSGs in the development of studies.
- To develop work with the Biomarkers Advisory Group.
- To work closely with SPED (Screening Prevention and Early Diagnosis Group) 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 innovative trials of novel biomarker, point of care tests, and imaging approaches in primary care settings.

Appendix 4

Publications in the reporting year

DISCOVERY Programme (including the SYMPTOM Study)

Shephard EA, Neal RD, Rose PW, Walter FM, Hamilton WT. The symptoms of adult chronic and acute leukaemia before diagnosis: large primary care case-control studies using electronic records. *BJGP* 2016;66:132-133.

Shephard E, Neal RD, Rose P, Walter FM, Hamilton W. Quantifying the risk of Hodgkin lymphoma in symptomatic primary care patients: a case-control study using electronic records. *British Journal of General Practice* 2015;e289-293.

Shephard EA, Neal RD, Rose PW, Walter FM, Hamilton WT. Quantifying the risk of non-Hodgkin lymphoma in symptomatic primary care patients aged ≥ 40 years: a large case-control study using electronic records. *Br J Gen Pract.* 2015;65(634):e281-8.

Hall N, Birt L, Banks J, Emery J, Mills K, Johnson M, Rubin GP, Hamilton W, Walter FM. Symptom appraisal and healthcare-seeking for symptoms suggestive of colorectal cancer: a qualitative study. *BMJ Open* 2015;5(10):e008448. doi: 10.1136/bmjopen-2015-008448.

Balasoorya-Smeekens C, Walter FM, Scott S. The role of emotions in time to presentation for symptoms suggestive of cancer: a systematic literature review of quantitative studies. *Psychooncology* 2015;24(12):1594-604. doi: 10.1002/pon.3833.

Banks J, Hamilton W, Walter FM. The Discovery Programme and its impact on cancer diagnostics. *Br J Hosp Med.* 2015;76(10):558-9. doi: 10.12968/hmed.2015.76.10.558.

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. March 2015

ICBP MODULE 4

Weller D, Vedsted P, Anandan C, Zalounina A, Fourkala EO, Desai R, Liston W, Jensen H, Barisic A, Gavin A, Grunfeld E, Lambe M, Law R, Malmberg M, Neal RD, Kalsi J, Turner D, White V, Bomb M, Menon U. Measuring routes to a diagnosis of cancer and diagnostic intervals in ten jurisdictions: methods used in the International Cancer Benchmarking Partnership, Module 4. *BMJ Open (accepted)*

ASICA

Murchie P, Allan JL, Brant W, Dennis M, Hall S, Masthoff J, Walter FM, Johnston M. Total skin self-examination at home for people treated for cutaneous melanoma: development and pilot of a digital intervention. *BMJ Open*, 2015; 6;5(8):e007993. doi: 10.1136/bmjopen-2015-007993.

MelaTools programme & Melanoma interview study

Scott SE, Birt L, Cavers D, Shah N, Campbell C, Walter FM. Patient drawings of their melanoma: A novel approach to understanding symptom perception and appraisal prior to healthcare consultation. *Psychol Health.* 2015:1-14. doi: 10.1080/08870446.2015.1016943.

Walter FM, Abel G, Lyratzopoulos G, Melia J, Greenberg G, Brewster DH, Butler H, Corrie P, Campbell C. Seasonal variation in diagnosis of invasive cutaneous melanoma in Eastern England and Scotland. *Cancer Epidemiol.* 2015;39(4):554-61. doi: 10.1016/j.canep.2015.06.006.

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Birt L, Scott S, Cavers D, Campbell C, Walter F. Member checking: a tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, In press.

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Appendix 5

Major international presentations in the reporting year

The Melanoma Interview Study & MelaTools programme

Walter FM. Evolving Role of Primary Care in Cancer conference, Victorian Comprehensive Cancer Centre, Melbourne, Australia. Keynote: 'Supporting early diagnosis of melanoma in primary care.' Mar 2016

DISCOVERY programme's Symptom study

Walter FM Oral presentation: 'Patient factors associated with time to diagnosis for pancreatic cancer: findings from an English prospective cohort study.' Evolving Role of Primary Care in Cancer conference, Victorian Comprehensive Cancer Centre, Melbourne, Australia, Mar 2016

MelaTools programme

Walter FM. Oral: melanoma seasonality study. NCIN cancer outcomes meeting, Belfast, N Ireland, June 2015

Walter FM. Oral: melanoma seasonality study. May 8th CaPRI annual meeting, Aarhus, Denmark, 2015

ICBP MODULE 4

Vedsted P et al. From first symptom to treatment for breast cancer – an international comparative study. Ca-PRI Boston 2016

Appendix 6

Strengths & weaknesses from the February 2016 Progress Review

Strengths:

- The written report was of high quality, thoughtfully written with clear direction indicated.
- Substantial progress has been made since the last review.
- The Panel praised the leadership of the Primary Care CSG.
- Achievements and impact from an international perspective were acknowledged and complimented.
- The structure of the Group appears to be functional and the benefit of a separate Primary Care CSG acknowledged (as opposed to having subgroups within other CSGs).

Issues for the CSG to consider:

- The Panel encouraged the Group in their plan to hold a Strategy Day as a matter of urgency in order to take forward their ideas (integrated risk profiling, biomarker development, patient journey, etc.) and to develop a well formed strategy. This should include the Group's strategic response to challenges laid down by external events such as:
 - NHS reforms
 - The Cancer Taskforce report (Achieving world-class cancer outcomes: a strategy for England 2015-2020)
 - The Lancet Oncology Commission on the expanding role of primary care in cancer control
 - NICE guidelines recommendations
 - Opportunities available from funders (funders are interested in being influenced)
 - Discussions with other CSG Chairs to explore their previous experiences
- Implementation of the work that the CSG has done so far was considered important.
- The Review Panel urged the Group to organise an annual meeting (perhaps linked with the RCGP).
- The Review Panel challenged the Group to be more ambitious, both nationally and as international leaders.
- The group is encouraged to make further proactive outreach to other groups.
- The group is encouraged to take the NHS health checks as an opportunity – build in early screening and integrate risk profiling and risk stratification.
- Use membership rotations to:
 - Recruit at least one oncologist onto the CSG
 - Consider recruiting a biomarker expert/translational scientist
 - Involve a health services researcher with implementation expertise
 - Recruit an expert in late effects for the Survivorship subgroup
- The Review Panel encouraged exploration of a James Lind Alliance (JLA) Priority Setting Partnership.

Issues for the NCRI/NIHR CRN to consider:

- Explore the feasibility of linking Cancer and Primary Care at the LCRN level.