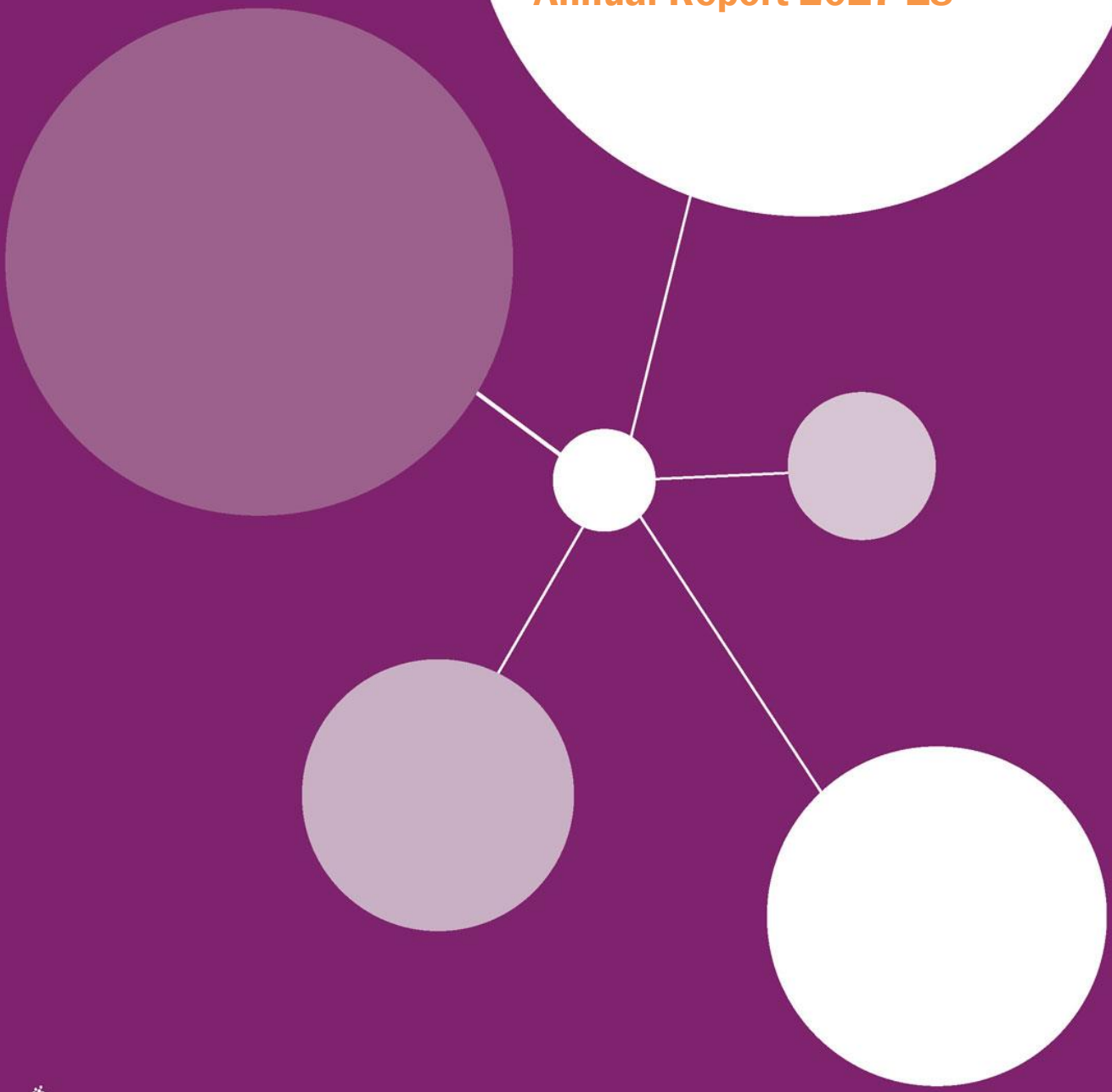
NCRI
National
Cancer
Research
Institute

NCRI Primary Care Clinical Studies Group

Annual Report 2017-18



Partners in cancer research

NCRI Primary Care CSG
Annual Report 2017-18

1. Top 3 achievements in the reporting year

Achievement 1

A key highlight of the last year has been the grant success for the planned Yorkshire Lung Screening Trial (YLST) with £6 million funding investment from Yorkshire Cancer Research over 6 years and the trial currently in set up. YLST will evaluate a strategy of invitation to low dose CT screening for lung cancer in mobile vans based in the community in the Leeds area in a target of 62,980 individuals. The strategy relies on identification of patients at risk from GP data, aims to maximise participation of invitees and incorporates a comparison of 3 different risk criteria for lung cancer screening. Professor Richard Neal (Primary CSG Chair) is Primary Care Lead for the trial and Dr Rhian Gabe is the lead methodologist (Primary CSG, Screening Subgroup member and incoming Screening Subgroup Chair). This is a joint study with our colleagues on the Lung CSG.

Achievement 2

Another highlight has been recruitment to the large Cancer Research UK-funded Barrett's oESophagus Trial (BEST3), a randomised controlled trial comparing the Cytosponge™-TFF3 test with usual care to facilitate the diagnosis of oesophageal pre-cancer in primary care patients with chronic acid reflux. As of 1st April 2018, 79 general practices from across a number of regions had been randomised, with 5683 patients recruited into the study, and 24% of invited participants consenting to the Cytosponge procedure in the primary care setting. Most patients rated this experience as acceptable (mean 8.2/10). Dr Fiona Walter (Cambridge, Early Diagnosis Subgroup Chair) and Professor Greg Rubin (Newcastle) are primary care leads for the trial which is led by Professor Rebecca Fitzgerald and colleagues from the Upper Gastrointestinal CSG with Professor Peter Sasieni and the Barts Clinical Trials Unit team.

Achievement 3

During this year, the CLASP (Cancer Life Affirming Support in Primary care) research programme, which is trialling internet-based lifestyle and well-being support to survivors of breast, prostate and colorectal cancer, has completed the feasibility stage and gained approval from NIHR to commence to full trial with an internal pilot. As of April 2018, trial recruitment is ahead of target with 500 patients randomised and over 130 practices involved. Professor Paul Little (Southampton) and Professor Lucy Yardley (Southampton/Oxford) are co-

Pls for the study, Professor Eila Watson (Oxford Brookes, Screening Subgroup Chair) and Richard Neal (Leeds) are co-applicants.

2. Structure of the Group

There have been no structural changes to the CSG in the reporting year.

This year we have welcomed Dr Juliet Usher-Smith and Dr Suzanne Scott as members of the CSG. We hope that they will enhance our portfolio in the field of cancer prevention.

Dr Christine Campbell, who recently rotated off the Group, was thanked for her fantastic service to the CSG particularly as outgoing chair of the Screening Subgroup. The group congratulate Dr Gabe who has been appointed to take over as Chair of the Screening Subgroup.

We also thank our trainees, Dr Rosalind Adam and Dr Helen Creedon, who have now rotated off the Group.

3. CSG & Subgroup strategies

Main CSG

Increase the number of studies on the portfolio, the number of accruals to studies and the breadth of studies across the cancer continuum and different cancers

With the number of new, large studies in set up, we expect increasing accruals over the coming year.

Consider undertaking some form of 'Priority Setting Exercise' in 12 months' time if we feel that existing documents are not providing enough strategic direction

The CSG reviewed this during the year, as mandated by the strategy document. The clear consensus of the CSG was that undertaking a specific 'primary care' priority setting exercise is not necessary at this point in time, given that other site-specific exercises have been published, or will be soon (e.g. colorectal, brain, endometrial, TYA, living with and beyond). Additionally, the SPED Advisory Group is undertaking a review of RCTs of all SPED activity. This will also inform our work.

Use existing (and upcoming/new) research priorities to drive our research agenda

Our subgroups are aware of published research priorities and these have informed our work (for example Macmillan Research Call, Breast Cancer Now Gap Analysis, Bowel Cancer UK Gap Analysis). When new trainees are appointed later in the year, it is the intention to task at least one of them to collate and synthesise all relevant topics from all of these documents, in order to inform priorities that the CSG may choose to pursue.

Work with other CSGs (both cross-cutting and site-specific) in the development of studies

The resources of the CSG are spread quite thinly such that working with lots of other CSGs is challenging (see 'challenges').

At the recent QQR for the Supportive & Palliative Care CSG, there was a recommendation that the three cross-cutting CSGs discuss how they may work more closely together. The Primary Care CSG welcomes and is very supportive of this initiative. A meeting is now scheduled for July 2018.

Several CSG and subgroup members also sit on other CSGs and their subgroups. These include: Brain CSG (Professor Neal), Skin Cancer CSG (Professor Walter), SPED (Dr Walter, Professor Neal, Dr Peter Murchie, Dr Thomas Round). Psychosocial Oncology & Survivorship CSG (Professor Watson), Localised Prostate Cancer Subgroup (Dr Gabe).

Examples of particular projects that have been developed, or are being developed, with other CSGs include:

- Yorkshire Lung Screening Trial & ELCID2 (Professor Neal & Dr Gabe working with members of the Lung CSG);

- Survivorship Subgroup (Professor Watson, Mrs Jan Rose, Mr Peter Donnelly) preparing NIHR PGfAR application jointly with Psychosocial Oncology and Survivorship CSG;
- Supporting Women with AdhErence to Endocrine Therapy (SWEET) – Professor Watson is joint co-PIs, the application will be submitted in July.
- PREDICT, a biomarker STHLM3 UK validation RCT is under final review with Prostate Cancer UK: Dr Gabe (PC) and Professor Hashim Ahmed (Prostate) are co-PIs, with investigators Dr Walter and other members of Prostate CSG;
- An application to Cancer Research UK's Early Detection committee, about population-based early detection of colorectal cancer, evaluating the use of circulating tumour DNA, led by Professor Ian Tomlinson (Birmingham) and members of the Colorectal Cancer CSG with Walter as co-investigator;
- An application to SCaRF, led by Dr Rubina Matin (Oxford), member of the Skin Cancer CSG and Walter, exploring unmet needs and attitudes to skin self-examination in melanoma survivors (EUNASS Study);
- CanTest PhDs are being developed with co-supervision by members of other CSGs, including Bladder & Renal CSG (Mr Grant Stewart), Gynaecological Cancer CSG (Dr Emma Crosbie) and Lung Cancer CSG (Dr Matthew Callister).

Work towards hosting first Annual Trials/Studies Meeting

This has continued to be difficult and has been the subject of ongoing work to try and solve. One of our trainee members did a lot of work on this. Ongoing issues, as compared with site-specific groups are that: our 'target audience' is primary care (50K GPs + their staff); difficulty in 'piggy backing' a Trials Day onto another relevant get-together of people; and a lack of funding (lack of potential sponsors from industry for primary care). At the autumn CSG we were very pleased that the NCRI Executive were open to consider alternative models of holding a Annual Trials Meeting and we have convened a small group to work on these. In particular, we are exploring the possibility of holding a joint meeting with both CRUK and Macmillan GP facilitators.

Maximise consumer input into all of our work through our consumer members, the Consumer Forum and local consumers

All of our studies have, for several years, had consumer input from the outset. Our consumer members (see reports) are very pro-active, and link with the Consumer Forum.

One highlight is that the CRUK-funded CanTest Collaborative has a consumer (Mrs Margaret Johnson) as a co-applicant. She is leading the PPI group in this multi-institutional programme, and also taught on the first CanTest International School for Early Detection Research in Primary Care.

Local consumers have been fundamental in the design of the YLST and the co-production of all the public facing materials. This was crucial in getting CAG approval for the study

Increase focus on internationalism

We welcome the opportunity for greater focus and reporting of internationalism.

The CanTest Collaborative has five international partners. Studies coming out of this Collaborative should reach the portfolio during the coming year. The first CanTest International School for Cancer Detection Research in Primary Care welcomed researchers from the USA, Australia, The Netherlands and Denmark.

CSG and subgroup members contribute widely to Ca-PRI (Cancer and Primary Care International Research Network), including as members of the Steering Committee.

The UICC's 2018 World Cancer Congress is being hosted in Kuala Lumpar, and Early Diagnosis Subgroup members have been selected to chair two workshops in the 'Advances in Screening and Early Detection' track.

The Screening Subgroup has undertaken a large project in Malawi.

The Early Diagnosis Subgroup is undertaking a large project on symptomatic breast and cervical cancer in Sub-Saharan Africa. This is funded by the SAMRC with the Newton Fund, and is being co-led by Walter (Cambridge) with Dr Jennifer Moodley (University of Cape Town), with co-investigators in Uganda, SA and the UK. The project also supports masters and PhD students, 2 of whom spent January undertaking master's modules in Cambridge.

The Early Diagnosis Subgroup continues to have strong links with Australian colleagues, especially in Victoria at the Universities of Melbourne and Monash. Over the last year there was a significant BJC publication (Emery et al), reporting the Improving Rural Cancer Outcomes Trial (IRCO), a cluster-randomised controlled trial of a complex intervention to reduce time to diagnosis in rural cancer patients in Western Australia. Other on-going trials focus on early detection or timely diagnosis of lung and colorectal cancer and melanoma.

A prospective cohort study spanning Norway, Denmark, Sweden, Scotland, Belgium, and the Netherlands reported its findings on abdominal symptoms and cancer in the abdomen in this reporting year.

Lung cancer screening is an area of international interest and the YLST team plan to collaborate with a concurrent study being planned in Australia and Canada in order to increase the evidence-base with respect to risk stratification.

Members of the CSG (Dr Weller, Dr Campbell) are co-applicants on one of the projects that has been shortlisted for the Grand Challenge; this is led by researchers from the Netherlands.

Focus on research involving 'hard to reach' and disadvantaged groups, older people and those with multi-morbidity

We will have an increased focus on this over the coming year (see 'priorities') and encourage those with previous work and experience in this area to contribute to multi-disciplinary studies.

Encourage researchers to present relevant studies at SPED We have encouraged this and continue to do so.
Use a range of outcome measures, including quality of life and measures of patient centred outcomes of living with and beyond cancer Life After Prostate Cancer Diagnosis study has now completed and collected patients reported outcome data on over 30,000 men across the UK diagnosed with prostate cancer 18-42 months previously. This will continue to be pursued through Subgroups over the coming year.
Engage with GPs and other primary care staff, including through the Macmillan GP workforce See above – we are engaging with the Macmillan GP workforce in relation to a joint meeting.

Early Diagnosis Subgroup (Chair, Dr Fiona Walter)

Consider the application of theoretical approaches (e.g. Model of Pathways to Treatment) to developing targeted interventions Theoretical approaches such as the Model of Pathways to Treatment continue to underpin ongoing studies conducted by Early Diagnosis Subgroup members, such as the BRAcED study (PI Dr Walter), investigating early diagnosis of brain cancer, the POSTCARD study (PI Humphrys), exploring the pathway to oesophageal and gastric cancer diagnosis, and the USP study (PI Zhou), investigating possible missed opportunities prior to diagnosis with urological cancer. Attention has now turned to using similar theoretical approaches to develop targeted interventions. A good example is the WICKED programme (PI Professor Neal), which is using the Behaviour Change Wheel (Michie et al) to support the development of an intervention to expedite cancer diagnosis through primary care.
Develop a toolkit for understanding beliefs and attitudes No progress to report.
Focus on groups with less favourable outcomes e.g. children & YA, co-morbidities, minorities, socio-economic deprivation There is a broad variety of newly funded ongoing work being conducted among the Early Diagnosis Subgroup members aimed reducing inequalities and maximising the impact of cancer symptom awareness and help-seeking, and optimise time to presentation with possible cancer symptoms.

These include:

- the LUSH study (funded by CRUK and PI Brain, Cardiff) investigating lung symptom awareness and health, now in write up
- the ABACus trial (funded by Yorkshire Cancer Research and PI Brain, Cardiff), a RCT of the health check intervention to improve cancer symptom awareness and help seeking among people living in socioeconomically deprived communities, currently recruiting
- the PEOPLE-HULL study (also funded by Yorkshire Cancer Research and PI Macleod, Hull), investigating primary care and community engagement to optimise time to presentation with lung cancer symptoms in Hull.

An application to Yorkshire Cancer Research, investigating ways to improve cancer symptom awareness among older Pakistani men and women in Yorkshire (PIs Whitaker & Marlow), was not successful.

Consider novel biomarkers and technologies in the development of portfolio studies

Several applications and newly funded work investigate the role of novel biomarkers and technologies in the early detection and diagnosis of cancer in primary care. As noted above, in Achievement 2, the large, CRUK-funded BEST3 randomised controlled trial (PI Fitzgerald) is comparing a combination of a new technology, the Cytosponge, with a biomarker panel, the TFF3 test, with usual care to facilitate the diagnosis of oesophageal pre-cancer in primary care patients with chronic acid reflux. To date, almost 80 general practices and 5700 patients have been recruited.

The NIHR-funded MelaTools SSM trial (PI Dr Walter) is evaluating the use of an app to undertake skin self-monitoring (SSM) among people identified via primary care as at higher risk of melanoma. The ECASS trial (PIs Rubin, Walter, Neal) is evaluating a computer aid for assessing upper gastro-intestinal symptoms in primary care, set in 42 practices in NE and East England. It arose from collaborations developed in the Early Diagnosis Subgroup, and is evaluating a gastric and oesophageal cancer risk assessment tool which arose from the highly successful NIHR-funded DISCOVERY programme.

Also mentioned above is the ambitious PREDICT trial, in final submission to Prostate Cancer UK. This seeks to evaluate the STKLM3 panel, comprising 5 biomarkers and developed in Sweden, in a UK primary care population with a greater proportion of black men.

Use more targeted approaches including risk-stratification in the development of portfolio studies

The NIHR-funded MelaTools SSM trial (PI Dr Walter) uses risk stratification to identify people at higher risk of melanoma to recruit for using an app to undertake skin self-monitoring.

This is a priority for developing new studies over the coming year.

Screening Subgroup (Chair, Dr Rhian Gabe/Dr Christine Campbell)

Consider risk-stratification in the development of portfolio studies

As detailed above, one of the key highlights of this year has been obtaining funding for the YLST and a primary objective of this study is to compare three criteria for identifying patients at high risk of lung-cancer in order to optimise future risk-stratification for a potential screening programme.

In addition, ProGREsS (Personalised Genetic risk estimates for cancer screening and prevention) is in set up pending HRA approval (see minutes from Primary Care CSG October 2017).

Consider new technology and how it might change behaviour along with FIT (including threshold) in the development of portfolio studies

Work in this area crosses a number of cancers including lung cancer screening, e.g. work investigating patient experiences of, and psychological responses to, lung cancer screening and development of an app-based booking for cervical screening.

Consider how to act as a conduit/facilitator for the stakeholders in this field

There was a well-received 'Primary Care and Cancer Screening Research day' held in London March 2016 which brought together around 70 stakeholders in the field with research presented across the major and new or potential screening areas. As a result of this and a scoping exercise by Helen Creedon (Trainee) and Christine Campbell (Subgroup Chair) a need has been highlighted for research relevant to a number of cancers addressing: over-diagnosis, risk stratification, uptake rates, hard to reach groups, inequalities, location of services, communication of results, exit points for older invitees and the interface between screening and symptoms in primary care. In addition, the impact of vaccination, HPV testing and self-sampling was important for cervical screening, while issues around national roll-out were of relevance to ovarian screening and changing the dialogue and stigma associated with smoking related illness for lung cancer. These areas will help inform future strategy for the group.

Consider inequalities agenda including health literacy and informed choice in the development of portfolio studies

There is a broad variety of newly funded ongoing work being conducted among the subgroup members aimed reducing inequalities and maximising the impact of cervical cancer control policies, HPV testing and uptake of lung cancer screening.

Consider the incentivisation of participation and health checks in the development of portfolio studies

No progress to report.

Survivorship Subgroup (Chairs, Professor Eila Watson)

Consider the need to be responsive to the ways in which services are delivered

This is now integral to all of our work.

Consider integration between primary & secondary care

This is now integral to all of our work.

Consider recurrence, detecting early & reducing fears of recurrence in the development of portfolio studies

The Cancer Research UK funded study (PI Dr Campbell) on Second Primary Cancers is progressing well, and scheduled to finish in mid-July 2018. The systematic review to examine the pathways to diagnosis and associated patient and healthcare practitioners' experiences identified forty-nine articles for inclusion with the most commonly reported SPCs being breast, lung, colorectal, and melanoma. The routes to detection (whether the SPC was diagnosed during routine follow-up/surveillance, or self-referral) varied by cancer type. In another component, survival outcomes following an SPC diagnosis using three linked databases of Scotland cancer patients are being examined: 37,193 people diagnosed with an SPC are included, and analyses are ongoing. In the third strand, interviews with patients and GPs are near completion. Preliminary results were presented at the Ca-PRI conference in Groningen, April 2018.

The Cancer Research UK-funded ASICA study, aiming to Achieve Self-directed Integrated Cancer Aftercare in melanoma, is set in Aberdeen, Scotland, and Cambridge, England. The Scottish end has just started recruitment and the Cambridge end is completing set-up.

Use biomarkers in relation to predicting who will develop recurrence or late effects

This is a priority for the Subgroup to take forward in the coming year. Dr Brian Nicholson has conducted a review of biomarkers for detecting recurrence of testicular cancer and methods are now being developed for an analysis of a Testicular Cancer follow-up database.

Consider multiple morbidities/ frailty/disadvantaged groups in the development of portfolio studies

The CSO Scotland funded study on Constructing life beyond cancer with comorbid disease (Cavers & Campbell) is progressing well. The systematic review of the qualitative evidence on the experience of cancer and comorbid illness from the perspective of patients, carers and health care professionals is near completion and the protocol published; the patient consultation exercise has been completed and is being written up; documents for the research ethics submission for the next major component, interviews with patients, are in development with interviews scheduled to start in late summer. Preliminary results were presented at the British Psycho-Oncology Society (BPOS) meeting in Oxford in March 2018, and at the Ca-PRI conference in Groningen, April 2018.

Support adherence to endocrine therapies NIHR PGfAR application will be submitted in July 2018
Consider nutrition and cancer in the development of portfolio studies Professor Watson, Russell, and Dr Sunil Dolwani are members of the NIHR Cancer and Nutrition Collaborative (Living with and Beyond Cancer initiative). This group is working to develop portfolio studies in this area. Pancreatic Cancer Experiences and Needs Survey (ongoing portfolio study) is addressing nutrition.

4. Task groups/Working parties

The Primary Care 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

Cancer Research UK Clinical Research Committee (CRUK CRC)				
Study	**Application type**	**CI**	**Outcome**	**Level of CSG input**
May 2017				
None				
November 2017				
Circulating tumour DNA to identify patients with cancer in primary care	Biomarker Project Award (Full Application)	Professor Anna Schuh	Not funded	Supporting letter
Other committees				
Study	**Committee & application type**	**CI**	**Outcome**	**Level of CSG input**
Symptom appraisal following primary breast cancer: promoting timely presentation to health services with possible symptoms of recurrence	Macmillan	Brindle	Not funded	Subgroup co-applicants [From last year's report as outcome was pending at the time]
Fears of cancer recurrence: using digital technology to aid self-management	Macmillan	Ashley	Not funded	Joint study with POS CSG - subgroup co-apps [From last year's report as outcome was pending at the time]
Improving patient-centred outcomes following a diagnosis of cancer: enhancing the role of primary care	Macmillan	Watson (+ Subgroup co-apps)	Not funded	Subgroup co-apps [From last year's report as outcome was pending at the time]
Demonstrating the feasibility of a Learning Health System for cancer diagnosis in Primary Care	CRUK Population Research Committee	Delaney	Funded	CSG provided advice & letter of support

A prospective randomised study of screening for bladder and kidney cancer in populations with high disease specific mortality risk	YCR	Catto	Pending	Professor Neal co-applicant
Adapting the Safety Net Shared Action Plan intervention for the South Asian community to promote greater patient involvement in achieving a faster cancer diagnosis in primary care	YCR	O'Hara	Pending	Professor Neal co-applicant
"A safety-netting intervention (Shared Safety Net Action Plan) to support re-attendance in primary care following presentation of potential cancer symptoms: a feasibility study	NIHR RfPB	O'Hara	Pending	Professor Neal co-applicant
Implementing LDCT screening for lung cancer in high-risk groups: exploring the attitudes of GPs and their self-efficacy to support patients during the screening pathway	CRUK Population Research Committee	Waller	Pending	Professor Neal collaborator
Examining the Rural Patient: A qualitative exploration of rural people's patient and primary care intervals	CRUK Postdoctoral Fellowship	Dobson	Not funded	Professor Neal host & Letter of support
YLST Biomarkers Sub-Study	YCR	Crosbie	Funded	Advice
The effect of adding a personalised smoking cessation intervention to a lung cancer screening programme	YCR	Murray	Funded	Professor Neal co-applicant
Clinical decision support for suspected cancer: implementation in primary care and long term follow-up	DH Policy Unit	Rubin	Funded	Dr Walter, Neal co-applicants
Policy Research Unite in Cancer Awareness, Screening and Early Diagnosis	DH	Duffy	Funded	Drs Walter, Mitchell, and Professor Neal co-applicants
Recognition, Understandings of, and Responses to Colorectal Symptoms Among people Living in rural Localities of Yorkshire	YCR	Dobson	Funded	Advice & letter of support
Feasibility testing an Acceptance and Commitment Therapy (ACT) interventION for improving	YCR	Smith	Funded	Professor Neal co-applicant

medication-taking behaviour in women with early stage invasive breast cancer: The ACTION trial				
Knowledge, attitudes and current practice of health professionals Knowledge, attitudes and current practice of health professionals regarding use of e-cigarettes and other smoking cessation interventions in cancer survivors	CRUK	Brett	Funded	Professor Watson and Dr Nicholson (Survivorship Subgroup, previous CSG Trainee)
Experiences and needs of patients with Pancreatic Cancer	Pancreatic Cancer UK	Watson	Funded	Professor Watson (CSG member and Subgroup Chair) is PI. Linked with Upper GI CSG in developing application and will discuss findings with Upper GI, SPC and POS as well as PCCSG.
PREDICT - Prostate Risk Evaluation using Diagnostic Innovations in Community Testing	Prostate Cancer UK	Ahmed	Pending	Dr Gabe (CSG member and Subgroup Chair) is Co-CI. Walter (CSG member and Subgroup Chair) is co-applicant. Link with Prostate CSG (Ahmed, Prostate CSG Chair, Heer subgroup Chair).
Patient experiences of, and psychological responses to, lung cancer screening;	Roy Castle Lung Cancer Foundation project grant	Waller & Quaife	Funded	Professor Waller (Screening Subgroup member)
HPV testing in cervical cancer screening: using behavioural science to understand anxiety and attendance	NIHR PhD studentship:	McBride	Funded	Professor Waller (Screening Subgroup member co-applicant)
App-based booking for cervical screening – commissioned service evaluation	UCLH	Waller	Funded	Professor Waller (Screening Subgroup member)
Cancer Communication & Screening	CRUK programme grant	Waller (Jane Wardle)	Not Funded	Professor Waller (Screening Subgroup member)

Uptake of lung cancer screening with high-risk groups: harnessing psychological targets for intervention	CRUK post-fellowship	Quaife	Funded	Professor Waller (Screening Subgroup member co-applicant)
Assessing the potential impact of introducing risk stratification using phenotypic or genomic information into the current English bowel screening programme.	Bowel Cancer UK.	Usher-Smith	Funded	Dr Walter co-applicant
Population-based early detection of colorectal cancer: a pilot project to evaluate the use of circulating tumour DNA.	CRUK ED Committee	Tomlinson	Pending	Dr Walter co-applicant
AIDx- Artificial Intelligence for early cancer Detection	CRUK Grand Challenge	Gerstung	Not funded	Drs Walter & Whitaker (Early Diagnosis Subgroup Chair & member co-applicants)
Improving cancer symptom awareness among older Pakistani men and women in Yorkshire.	YCR	Whitaker & Marlow	Not funded	Dr Whitaker (Early Diagnosis Subgroup member)
Development of a community-based intervention to increase bowel screening uptake in South Asians living in a diverse area of Oxford City (OX4): a mixed methods study	Bowel Cancer UK	Smith	Funded	Professor Watson co-applicant
What is the clinical-effectiveness and cost-effectiveness of embedded risk-of-cancer assessment of patients in primary care; the ERICA trial	Charitable donation D&M Gillings	Hamilton	Funded	Discussions with Early Diagnosis Subgroup

6. Consumer involvement

Jan Rose

I am involved with early diagnosis, screening and survivorship projects with the Primary Care Clinical Studies Group and belong to the Screening and Survivorship Subgroups. I contribute and make an impact as follows: I comment from the patient perspective with honesty, with personal experience, with experience having been a carer of a cancer patient, sometimes more generally with knowledge of simply being a cancer patient. In doing so, I believe it keeps the research and discussions focused on benefit to patients.

- I have supported dissemination of the paper 'Talking about human papillomavirus (HPV) and cancer: development of consultation guides through lay and professional stakeholder co-production using qualitative, quantitative and secondary data' (on Survivorship Subgroup portfolio) by using my contacts locally, regionally and nationally. I have shared this with the NCRI Consumer Forum to raise awareness of the results.
- I have contributed to the plain English summary for several projects, the writing of information sheets for patient participants and given advice on patient and public involvement for projects and provided letters of support for the research.
- As Patient Representative on the Management and Advisory Groups of the project WICKED (Wales Interventions and Cancer Knowledge about Early Diagnosis) I ensure that the patient voice is listened to and is central to the design of the various work packages in the project. With the researchers, I will make sure the interventions that are finally developed are patient friendly and therefore more likely to be successful working in practice.
- I have explained my role and support for CATRIC (Communication about Tests and Referral to Investigate Causes of ill health) to the ethics committee.
- I attended the Cancer of Unknown Primary and Acute Oncology Workshop supported by the NCRI and NIHR. I will share outcomes of the day with the Primary Care Clinical Studies Group so that we can consider what it can do and what links it might have with other clinical studies groups in this area of work. I have informed the Consumer Forum members about this event to raise awareness with consumers in all the clinical studies groups.

I value the support I get from the Consumer Forum. Sharing knowledge and collaborating with all consumer members is important. Attending the Cancer Conference in November has helped develop my knowledge and confidence to participate fully with the health researchers on the Primary Care CSG and when working on specific research projects.

Ann Russell

I am intrinsically involved in all the groups and activities with which I am associated, contributing to discussions and actions ensuring patient benefit is always at the forefront. Some of my activities:

- Co-applicant study 'Follow up after breast cancer surgery'. Suggested and undertook survey of breast cancer patients/ICPV; on behalf of Survivorship Subgroup. 13 ICPV members contacted all responded.
- Responded to request from Oxford Brookes University PhD student - Nutrition and Pelvic Cancer. Introduced questionnaire to colorectal groups, many responded.

- Cancer and Nutrition Collaboration Research. Signs that work that I'm very much involved with is beginning to make a difference to the way people are thinking with respect to nutrition.
- Member of Management group 2 physical exercise programmes for colorectal cancer patients (one an international). Work I'm doing gaining traction, more interest being shown in prevention and survivorship.
- FOCUS4. Recent joint meeting of the IDMC /TSC successfully submitted suggestions to continue supporting areas of this trial experiencing a number of unfortunate difficulties.
- Leeds Beckett University Professor asked me to help design proposal for systematic review 'Effectiveness of digital supportive interventions for people with cancer that cannot be cured'. My suggestions been taken up. Have been thanked by for my contributions helping make review truly relevant for patients.
- Member of CBCR Unit. Together with Programme Co-ordinator, 2 other patients, contributed to production of first patient newsletter for patients in Personalised Breast Cancer Programme.
- Discussions with cancer patient groups showing increasing number of people living with other conditions/diseases. Been asked to raise this with CSG hoping future research projects, pertinent to portfolio, may be forthcoming collaborating with other CSGs.
- Preliminary discussion with TYA CSG member asking if there could be link between Primary Care CSG and TYA following JLA cancer priority setting exercise. Raised this with Dr Walter, Chair Early Diagnosis Subgroup.
- March 2018 Consumer Forum Dragons Den session (CRUK Biomarker Application: VMPRASS) personally thanked by Alex Lee, Protein Networks team at ICR, "for very helpful comments and feedback" regarding patients' QoL issues.

Resulting from my involvement and activities to date, I was asked by Professor at University of California, subsequently recruited as patient advocate, for CRUK Grand Challenge project. Exciting project spans 5 countries and within the group patient involvement in UK has been acknowledged as being well in advance of others.

7. Priorities and challenges for the forthcoming year

Priority 1

Strategic Objective 1.16 'Considering work in Prevention'

This objective is to: 'Consider opportunities for developing studies in prevention (currently with the Subgroup structure)'.

We have made progress on this with the appointment of Juliet Usher Smith to the main CSG. Her role will be as a 'Prevention Champion' for the CSG. Initially, we were planning to set up a Working Group to scope the current extent of prevention research. However, we then became aware of an initiative led by the two trainees on SPED. They are undertaking a scoping review of trials in screening, prevention and early detection. Once this piece of work is complete, we will consider its findings and find a direction, and a structure, to take the prevention agenda forwards. It may be that we do indeed need a dedicated Working Group in due course.

Priority 2

Strategic Objective 1.3 'Priority Setting'

The JLA 'Living with and Beyond Cancer' priority setting exercise will be published later this year. It is hoped that the recommendations will be picked up by funding bodies. The Primary Care CSG, and in particular the Survivorship Subgroup (possibly in collaboration with the Psychosocial Oncology & Survivorship CSG and the Supportive & Palliative Care CSG) will be in a strong position to address some of the priorities. The Subgroup will therefore ensure that it positions itself well and is able to respond quickly when the report is published. This is likely to be an important driver of the Subgroup's work over the next few years.

Priority 3

Strategic Objective 1.8 Focus on research involving 'hard to reach' and disadvantaged groups, older people, and those with multi-morbidity

This is an area where we haven't specifically focused. However, some of our studies do focus on recruiting patients from disadvantaged areas (for example, Yorkshire Lung Screening Trial, and ABACUS3). All three Subgroups will focus on this in the coming year, working together where necessary. Indeed, we are considering developing a proposal that cuts across our three Subgroups possibly focusing on multi-morbidity.

Work will also be informed by established research priorities.

Challenge 1

Changes in personnel

For several years there have been few changes in personnel within the CSG structure. This has fostered a degree of stability and productivity. However, this situation is changing, and it will be a challenge to continue, and indeed expand current levels of activity. After long service to the CSG, Dr Campbell has rotated off the CSG and Dr Gabe has been recently appointed as the new Chair of the Screening Subgroup. Both Professor Watson Dr Walter will be rotating off the CSG during the coming year, and new Chairs of both Survivorship and Early Diagnosis

Subgroups will need to be appointed. However, these Subgroups are strong and we expect to make good appointments.

However, the work of the Subgroups is largely directed by the strategy we are confident of a relatively smooth transition. The direction of work of the Screening Subgroup will be informed by the scoping exercise project that was undertaken by a trainee member over the past year. Other work (e.g. the scoping review by SPED, and the Living With And Beyond James Lind Alliance outcomes) will also inform the direction of work of all three Subgroups.

Challenge 2

Portfolio

In last year's report (and indeed previous years) we discussed the ongoing challenge of ensuring that all the portfolio studies are correctly allocated, and that where studies need to be double badged that there are done so correctly (an example of this would be BEST3 which is recruiting in primary care yet badged as an Upper Gastrointestinal CSG study, and we see potential problems with the Yorkshire Lung Screening Study). At present we feel that the portfolio does not currently do justice to our work. It also feels like unnecessary and unwanted work for the Chair and Subgroup Chairs to constantly have to try and chase these issues up.

Additionally, we felt that there was a recognition within NCRI that other high-quality studies (e.g. observational studies of routine data) were valued and could be 'counted' as part of a CSG's work. However, we see no translation of this in practice, to date. This has been frustrating for the Primary Care CSG, as much important high-quality and high-impact work is using such studies. This is evidenced by the nine papers that have been shortlisted for the RCGP Research Paper of the Year – none of these are trials or portfolio studies.

Challenge 3

Effective co-working with other CSGs

Throughout its existence the CSG has strived to work productively with many of the site specific and cross-cutting CSGs. We have had some success in doing this – especially with lung, brain, prostate and melanoma and Psychosocial Oncology and Survivorship. We have also had experience of a number of attempts at joint working that have been less productive. However, we feel that for various reasons that we haven't been able to do this as well as we would could have done, and that there is potential for better joint working in this area. SPED has been useful for improving the quality of proposals in this field, but hasn't – to date – been strategic in the future direction of research in this area.

Our resources, as a small CSG, are limited. We wonder whether there may be a better structure within NCRI CSGs for cross-working. We are not sure what it is, but would value thought and discussion on this.

We welcome the current initiative for members of the three cross-cutting CSGs to meet and discuss ways of working together better.

8. Appendices

Appendix 1 - Membership of main CSG and subgroups

Appendix 2 – CSG and Subgroup strategies

Appendix 3 - Portfolio Maps

Appendix 4 – Top 5 publications in reporting year

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

Professor Richard Neal (Primary Care CSG Chair)

Appendix 1

Membership of the Primary Care CSG

Name	Specialism	Location
Professor Paul Brocklehurst	Clinician Scientist	Bangor
Dr Rosalind Adam*	Clinical Lecturer	Aberdeen
Dr Helen Creedon*	Clinical Tutor Associate	Edinburgh
Mrs Janice Rose	Consumer	Gloucester
Mrs Ann Russell	Consumer	Cambridgeshire
Dr Sunil Dolwani	Gastroenterologist	Cardiff
Professor Richard Neal (Chair)	General Practitioner	Leeds
Dr Fiona Walter	General Practitioner	Cambridge
Professor David Weller	General Practitioner	Weller
Professor Eila Watson	Health Services Researcher	Oxford
Professor Andrew Wardley	Medical Oncologist	Manchester
Dr Thomas Round	PCRN Representative	London
Ms Julie Cunningham	Research Delivery Manager	London
Professor Lucy Brindle	Senior Lecturer	Southampton
Dr Peter Murchie	Senior Lecturer	Aberdeen
Dr Katriina Whitaker	Senior Lecturer and Lead in Cancer Care	Guildford
Dr Christine Campbell	Senior Research Fellow	Edinburgh
Dr Elizabeth Mitchell	Senior Research Fellow	Hull
Dr Rhian Gabe	Statistician	York

* denotes trainee member

Membership of the Subgroups

Early Diagnosis Subgroup		
Name	**Specialism**	**Location**
Mrs Margaret Johnson	Consumer	Cambridgeshire
Dr Brian Nicholson*	Doctoral student, General Practice	Oxford
Professor Willie Hamilton	General Practitioner	Exeter
Professor Paul Little	General Practitioner	Southampton
Dr Peter Murchie	General Practitioner	Aberdeen
Professor Richard Neal	General Practitioner	Leeds
Professor Greg Rubin	General Practitioner	Newcastle
Dr Fiona Walter (Chair)	General Practitioner	Cambridge
Dr Suzanne Scott	Health Psychology	London
Professor Georgios Lyratzopoulos	Public Health	Birmingham
Dr Katriina Whitaker	Senior Lecturer and Lead in Cancer Care	Surrey

Screening Subgroup		
Name	**Specialism**	**Location**
Professor Sue Moss	Cancer Epidemiology	London
Dr Paul Brocklehurst	Clinician Scientist	Bangor
Dr Helen Creedon	Clinical Tutor Associate	Edinburgh
Mrs Janice Rose	Consumer	Gloucester
Dr Sunil Dolwani	Gastroenterologist	Cardiff
Professor David Weller	General Practitioner	Edinburgh
Professor Clare Wilkinson	General Practitioner	Bangor
Mrs Anne Stevenson	National Programmes Lead, PHE Screening	Gloucester
Dr Jo Waller	Principle Research Associate	London
Professor Sheina Orbell	Psychologist	Essex
Dr Christine Campbell (Chair)	Senior Research Fellow	Edinburgh
Dr Anita Lim	Cancer Epidemiologist	London
Dr Rhian Gabe	Statistician	York

Survivorship Subgroup		
Name	**Specialism**	**Location**
Dr Brian Nicholson*	Clinical Fellow	Oxford
Mrs Janice Rose	Consumer	Gloucester
Dr Jim Elliot**		Newport
Dr Fiona Walter	General Practitioner	Cambridge
Professor David Weller	General Practitioner	Edinburgh
Professor Eila Watson (Chair)	Health Services Research	Oxford
Dr Lucy Brindle	Senior Lecturer	Southampton
Dr Nicola Gray	Senior Lecturer	Dundee
	Senior Lecturer	York
Dr Peter Murchie	Senior Lecturer	Aberdeen
Dr Gill Hubbard	Senior Research Fellow	Inverness
Mr Peter Donnelly**	Surgeon	Devon
Rosalind Adam		Aberdeen

* denotes trainee member

**denotes non-core member

Appendix 2

CSG & Subgroup Strategies

NCRI Primary Care Clinical Studies Group – Strategy 2017-2020 v3.0 June 2017

Purpose

This strategy has been produced to support the direction and work of the Primary Care CSG 2017 onwards. It will be reviewed and updated (by Chair and sub-group Chairs) on a regular basis.

Background and process

A Strategy Day was held in London on the 19th May 2016. Participants included members of the CSG, and key externally invited stakeholders. The day was facilitated by Prof Greg Rubin, and supported financially by Macmillan Cancer Support. An initial 'scene-setting' session was held and included a series of short presentations on a range of relevant topics, including: the current NCRI/CSG landscape; Consumer Forum; current CSG sub-group structure, environment and portfolio; the external QQR; the funding environment; Independent Cancer Taskforce; NHS challenges in devolved nations; Lancet Oncology Commission; Research Priority Setting; Existing research priorities; delivering the portfolio; SPED; and the Department of Health Policy Research Unit in Cancer Awareness, Screening and Early Diagnosis.

Following this there were group sessions on where the group saw itself in 3 years' time (covering: aspiration, defining and influencing the agenda, and how to measure success), and developing a strategy with timelines and responsibilities (by sub-group). The group work was informed by prior 'homework' of participants which included a 'SWOT' analysis, and questions about future important research areas and priorities. All the material generated on the day was collected and this strategy is the result of subsequent analysis by the Chair, sub-group chairs and CSG members.

Recent feedback on Annual Reports, and the feedback of the QRR panel were generally positive, and suggested no major changes to the ways in which the CSG functions. Indeed, in the QQR, the CSG was encouraged to be more ambitious and aspirational, both nationally and internationally.

Because in recent years the remit of the CSG has shifted to have more emphasis on identifying research priorities and opportunities and developing the portfolio, rather than delivering the portfolio *per se*, the work in developing this strategy has focused on this.

The development of the strategy was also driven by some of the weaknesses that were identified. These don't appear per se in the strategy, but have informed its development and are included here as a reminder.

Weaknesses

Working to reduce some of our perceived weaknesses including:	Working to solve other perceived weaknesses that we may have less control over:
▪ Lack of integration with specific tumour sites, genomics etc. ▪ Lack of trial representation ▪ Too few research groups that dominate the area ▪ Groups works as a collection of individuals rather than a team ▪ Horizon scanning of new technologies ▪ Resistance to new ideas ▪ Fragmentation of expertise across subgroups ▪ Capturing the full extent of research	▪ Lack of funding, limited number of funding opportunities ▪ Indistinct relationship with funders ▪ Lack of funding for strategy days/annual meetings ▪ Lack of up & coming researchers ▪ Competition within the group ▪ Ensuring a broad membership and a good geographical spread

Overall Aims of the CSG

To continue to expand the portfolio of the Primary Care CSG in coming years, in terms of:

- Number of studies
- Number of accruals to studies
- Breadth of studies across the cancer continuum and different cancers

List of initials

AR – Ann Russell, CSG consumer member
CC – Christine Campbell, Screening Sub-Group Chair
DW – David Weller, CSG member
EW – Eila Watson, Survivorship Sub-Group Chair
FW – Fiona Walter, Early Diagnosis Sub-Group Chair
JR – Janice Rose, CSG consumer member
PM – Peter Murchie, CSG member
RN – Richard Neal, CSG Chair
SD – Sunil Dolwani – CSG member
TR – Tom Round, CSG member

No.	Strategic objective	Action to be taken	CSG lead	Evidence by	Date/timescale	Outcome
	General issues					
1.1	Increasing the number of studies on the portfolio, the number of accruals and the breadth of studies across the cancer continuum and different cancers	To be achieved to fulfilling all of other objectives listed below	RN, CC, FW, EW, All members	Annual Reports	3 years – May 2020 / next QQR	
1.2	Using existing (and upcoming/new) research priorities to drive our research agenda	Subgroups to strategically search, identify and determine priorities from existing research priorities such as: ▪ Lancet Oncology Commission ▪ NICE Urgent cancer guidelines ▪ Independent Cancer Taskforce (England) (especially the 10 recommendations where the NCRI can have an impact) ▪ Other documents from the devolved nations (including new Scottish Cancer Plan) ▪ JLA survivorship (expected 2018) ▪ JLA TYA (expected 2017)	RN, CC, FW, EW	CSG papers Annual reports	Identified by summer 2017 Research priorities by Autumn 2017	
1.3	Considering undertaking some form of 'Priority Setting Exercise' in 12 months' time if we feel that existing documents are not giving us enough strategic direction in our work.	Review Autumn 2017 and decide whether action needed, and if so, plan action - which may take the form of a James Lind Alliance exercise, or a modified Delphi exercise, working with the consumer Forum	RN	Annual Report 2017-18	Review Autumn 2017 and, if needed, Priority Setting Exercise 'activated by mid-2018	
1.4	Working with other CSGs (both cross-cutting and site-specific) in the development of studies	Consistent approach to be developed to work with other CSGs and Advisory Groups	RN (with delegation for individual / groups of CSGs/AGs)	Increase in scope of future portfolio	3 years – May 2020 / next QQR	
1.5	Working towards hosting first Annual Trials/Studies Meeting	Exploratory/preparatory work with a view to hold 1st Annual Meeting in either Autumn 2017 or 2018	RN	Presence / absence of Annual Meeting by Autumn 2018	Late 2018	
1.6	Maximising consumer input into all of our work through our consumer members, the Consumer Forum and local consumers	Responsibility of all members and sub-group members to engage with Consumers	JR / AR & all members	Consumers to assess this in Annual Reports	Assess annually in Annual report	
1.7	Increasing focus on internationalism	Responsibility of all members and sub-group members to participate in, and promote, international research studies and dissemination of our work at international conferences	DW All members	Annual Reports	Assess annually in Annual report	
1.8	Focus on research involving 'hard to reach' and disadvantaged groups, older people, and those with multi-morbidity	Responsibility of all members and sub-group members to ensure that, where possible, hard to reach and disadvantaged groups are included – this is one strength of primary care	CC, FW, EW All members	Annual Reports	3 years – May 2020 / next QQR	

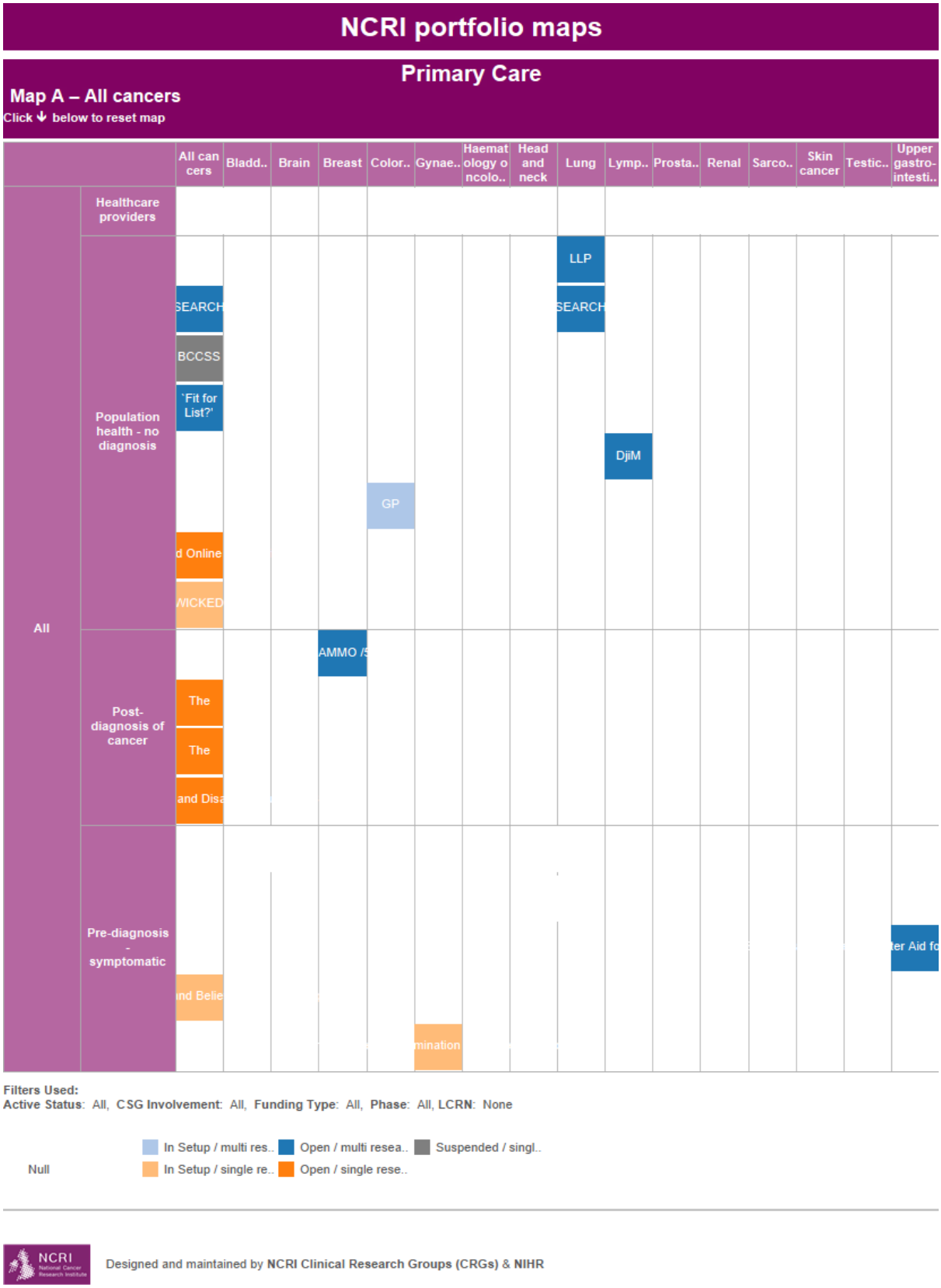
1.9	Encouraging researchers to present relevant studies at SPED	Consideration of submitting screening and ED studies for SPED workshops to improve quality, greater collaboration, and increased chances of funding	CC & SPED members (RN, FW, PM)	Annual Reports and SPED minutes	3 years – May 2020 / next QQR	
1.10	Using a range of outcome measures, including quality of life and measures of patient centred outcomes of living with and beyond cancer	The nature of primary care studies means that a range of outcome measures could – and should – be used across the portfolio, to ensure quality and relevance	CC, FW, EW	Outcomes as reported in portfolio studies	3 years – May 2020 / next QQR	
1.11	Engaging with GPs and other primary care staff, including through the Macmillan GP workforce	Engagement with primary care clinicians essential in order to: - Deliver portfolio - Help drive the research agenda - Increase quality of new proposals. This engagement may take several forms: though CRN; through proposed Annual Trials/Studies Meeting; through RCGP and other professional bodies; and through other ad hoc activities	TR	This is difficult to capture and record; however progress towards this will be presented in narrative format in Annual Reports	3 years – May 2020 / next QQR	
1.12	Contributing to, and presenting, our work at the NCRI conference	Engagement with NCRI conference in order to: Disseminate work from Primary Care CSG portfolio Make links with other 'applied', translational, and basic science researchers Improve quality and breadth of future portfolio	RN All members	NCRI conference programme and Annual Reports	3 years – May 2020 / next QQR	
1.13	Working closely with all of our funding bodies to ensure CSG's priorities are reflected in their calls as much as possible	Establish / maintain relationships with funders including NIHR, DH, Cancer Research UK, Macmillan Cancer Support, and other site specific (e.g. Prostate Cancer UK) and regional cancer charities (Yorkshire Cancer Research)	RN, CC, FW, EW	This is hard to measure but breadth and depth of funders in the portfolio and reported annually in Annual Reports will give some indication	3 years – May 2020 / next QQR	
1.14	Fully engaging with the Department of Health Policy Research Unit in Cancer Awareness, Screening and Early Diagnosis	Need to engage with DH PRU to ensure: - maximum 'fit' of our portfolio with that of DH PRU - cross fertilisation of ideas/methods. This will be done through identification of 'link' person and a standing item on our agenda	Identify a 'link' person within CSG and/or co-opt a researcher from DHPRU	Person identified by May 2018 Specific engagement to be described in Annual Reports	3 years – May 2020 / next QQR	
1.15	Fully engaging with new technologies and their assessment in our arena	A 'horizon-scanning' function is needed to ensure that evaluating and trialling of new innovations is timely and appropriate – and forms part of the Primary Care CSG portfolio. Achieved through devolved function to sub-groups as standing item	CC, FW, EW	Sub-group minutes, Annual Reports, number of new technologies on portfolio	3 years – May 2020 / next QQR	
1.16	Considering work in Prevention	Consider opportunities for developing studies in prevention (currently outwith sub-group structure)	TBC 'prevention champion' or co-opt	CSG minutes Annual Reports	Autumn 2017 and then annually	
1.17	Considering work in Nutrition	Consider opportunities for developing studies in nutrition	AR + SD	CSG minutes Annual Reports	Autumn 2017 and then annually	
1.18	Considering work around NHS (England) Health Checks	Consider opportunities for developing studies around NHS (England) Health Checks – eg opportunities to increase screening uptake, raise	RN & SG chairs	CSG minutes Annual Reports	Autumn 2017 and then annually	

		cancer awareness, and encourage preventative activities				
2.0	**Evaluation** Progress against this Strategy will be made assessed by the CSG's Annual Reports and the next QQR.	Evaluation of progress against all the objectives in the strategy	RN	CSG minutes Annual Reports Next QQR	3 years – May 2020 / next QQR	
3.0	**Standing items for sub-groups**	To consider each of the following as standing items within sub-groups (copied down from above): Review of existing and new published research priorities (item 1.2) Consumer involvement (item 1.6) Internationalism (item 1.7) Hard to reach and disadvantaged groups, older people, those with co-morbidities (item 1.8) Use of range of outcome measures (item 1.10) Working closely with funding bodies (item 1.13) Horizon scanning new technologies (item 1.15)	CC, FW, EW	Sub-group minutes and reports Annual reports	Review annually – ongoing	
4.0	**Specific research objectives (by sub-group)**					
4.1	**Screening** To consider the following in the development of portfolio studies: ▪ Risk-stratification ▪ New technology and how it might change behaviour ▪ FIT (including threshold) ▪ How to act as a conduit/facilitator for the stakeholders in this field ▪ Inequalities agenda – including – health literacy, informed choice ▪ Incentivisation of participation ▪ Health checks	The Screening subgroup to consider what additional expertise may be needed to develop programmes of work within the key areas, and identify where synergy exists with existing programmes of work The Screening subgroup to prioritise two or three projects to develop within next 6-12 months that involve cross-national and cross-institutional working (including submission to SPED), and set up working groups with timetables to take forward these and other studies For each new study ensure focused engagement with relevant site-specific CSGs Engage with NHS Screening Programmes (across all four nations) in evaluation research	CC Members of screening subgroup	Sub-group minutes and reports	Update on progress at six-monthly Primary Care CSG meeting 3 years – May 2020 / next QQR	
4.2	**Early diagnosis** To consider the following in the development of portfolio studies: • Application of theoretical approaches (e.g. Model of	The ED subgroup to consider what additional expertise may be needed to develop relevant applications, and consider refreshing group membership annually.	FW Members of ED subgroup	Sub-group minutes and reports	Update on progress at six-monthly Primary Care CSG meeting	

	Pathways to Treatment) to developing targeted interventions; • Develop a toolkit for understanding beliefs and attitudes • Focus on groups with less favourable outcomes e.g. children & YA, co-morbidities, minorities, socio-economic deprivation; • Novel biomarkers and technologies; • More targeted approaches, including risk-stratification .	The ED subgroup to consider building on existing programmes of work (e.g. CanTest, WICKED) to address delivery of key objectives. Engage with other national and international ED groups e.g. CRUK and the PRU, in order to ensure synergistic horizon scanning and collaborative planning and development of new work, including application of theoretical approaches. Engage with Imaging, Biomarker and SPED groups to enhance collaborations.			3 years – May 2020 / next QQR	
4.3	**Survivorship** To consider the following in the development of portfolio studies: ▪ Need to be responsive to the ways in which services are delivered ▪ Integration between primary & secondary care ▪ Recurrence –detecting early & reducing fears of recurrence ▪ The use of biomarkers in relation to predicting who will develop recurrence / late effects ▪ Multiple morbidities / frailty / disadvantaged groups ▪ Supporting adherence to endocrine therapies ▪ Nutrition and cancer	The Survivorship sub-group to: ensure membership rotation and consider additional expertise required to take forward identified priorities identify priority areas for the development of new projects which address strategic objectives, and establish timelines for proposal development and submission engage with NCRI initiatives to increase and strengthen research in the area of Living With and Beyond Cancer. build on existing collaborations and establish new collaborations with other CSGS continue to engage with the Macmillan GP network .	EW Sub-group members	Sub-group meeting minutes and reports Annual Reports	Update on progress at six-monthly Primary Care CSG meeting 3 years – May 2020 / next QQR	

Appendix 3

Portfolio maps



Appendix 4

Top 5 publications in the reporting year

Trial name & publication reference	Impact of the trial	CSG involvement in the trial
1. PROSPECTIV: Supporting prostate cancer survivors in primary care: findings from a mixed methods pilot study of a nurse-led psycho-educational intervention. Watson EK et European Journal of Oncology Nursing 2018; 32: 73-81	As hospital based follow-up is reducing in duration new models of care for cancer survivors are needed. This paper adds to the evidence base regarding prostate cancer survivorship care and has shown for the first time that it is feasible to train nurses in primary care to deliver a relatively low intensity, low cost intervention which is valued by men and is potentially cost-effective. This study has indicated that larger trials are warranted to confirm the effectiveness of primary care based interventions to support cancer survivors.	Portfolio study. Led by Professor Watson. Multiple other current and past CSG members as co-investigators. Developed through Survivorship Subgroup.
2. SYMPTOM: Understanding symptom appraisal and help-seeking in people with symptoms suggestive of pancreatic cancer: a qualitative study Mills K et al, BMJ Open, 2017;7(9):e015682.	Few studies have reported interviews with patients recently or subsequently found to have the difficult-to-diagnose pancreatic cancer. In order to understand symptom appraisal and help-seeking, this publication reports findings from a qualitative investigation of people referred to specialist care with potential symptoms. Set within a large prospective cohort study whose findings were reported in Lancet Gastroenterology & Hepatology (2016), this study provides novel insights into the	Portfolio study that was part of an NIHR PGfAR. Led by Walter. Multiple other current and past CSG members as co-investigators. Developed through Early Diagnosis Subgroup.

	intermittent nature of early GI symptoms and effects on eating patterns. Findings have been disseminated by leading charity, Pancreatic Cancer Action, and informed educational materials at the Royal College of GPs.	
3. TALKING HPV: Talking about human papillomavirus and cancer: development of consultation guides through lay and professional stakeholder coproduction using qualitative, quantitative and secondary data. Hendry M et BMJ Open. 2017 Jun 26;7(6):e015413.	The aim of this portfolio study was to design and test 'scripted consultations' comprising guidance sheets that doctors could use to guide conversations with their patients about human papillomavirus (HPV). HPVs cause all cervical cancer and the majority of vulvar, vaginal, anal, penile and oropharyngeal cancers. Many clinicians lack adequate knowledge or confidence to discuss sexual transmission and related sensitive issues. Complex information needs to be communicated to patients diagnosed with these in a clear, digestible, honest and salient way. This paper reports the development of the consultation guides and encompassed reviewing the evidence, and then prioritising, improving, and testing the messages. This is novel and important work that will influence communication. The final versions of the guidance sheets and information leaflets are available to download from the Bangor University website or via a link from the findings paper.	Portfolio study. Led by Dr Wilkinson. Multiple other current and past CSG members as co-investigators. Developed through Screening Subgroup.

4. NEGATIVE FOBt: The contribution of a negative colorectal screening test result to symptom appraisal and help-seeking behaviour among patients subsequently diagnosed with an interval colorectal cancer. Barnett KN et al, Health Expect. 2018 Feb 19.	The effect of a previously negative colorectal screening result on the presentation of intervals cancers was largely unknown. This recently published qualitative study interviewed patients with interval cancers. The findings – principally that most people did not suspect cancer as a possible cause of their symptoms – clearly identify the need for screening participants to be better informed of the limitations of screening and the possibility of an interval cancer.	Portfolio study. Led by Dr Campbell. Multiple other current and past CSG members as co-investigators. Developed through Screening Subgroup.
5. MELATOOLS: Identifying people at higher risk of melanoma across the UK: a primary care based electronic survey. Usher-Smith JA et, Brit J Dermatol, 2017;176(4):939-948.	Reporting findings from patients recruited from 22 general practices across N Wales, NE Scotland and E England, this study was among the first to collect patient data using tablets in general practices waiting rooms. The study showed this recruitment strategy is feasible and acceptable, as well as confirming that it is possible to risk-stratify the general practice population according to their future risk of melanoma. Subsequently, this approach has been used in a randomised controlled trial to identify people at higher risk of melanoma to receive targeted risk reduction information and instruction on using an app to monitor possible skin changes. This trial evidence supports the development of using risk-stratification and targeted interventions aiming at promoting	Portfolio study. Led by Dr Walter. Multiple other current and past CSG members as co-investigators. Developed through Early Diagnosis Subgroup.

	early cancer detection across a wide range of cancers in primary care.	

Appendix 5

Recruitment to the NIHR portfolio in the reporting year

In the Primary Care CSG portfolio, 12 trials closed to recruitment and 15 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	173	219	0	219	-	-
2014/2015	829	1	709	1	-	-
2015/2016*	27657	2412	6915	2391	-	-
2016/2017*	10128	2370	9884	1315	-	-
2017/2018*	6538	7035	4574	6627	-	-

*includes data of studies both led by Cancer and supported by Primary Care and led by Primary Care and supported by Cancer