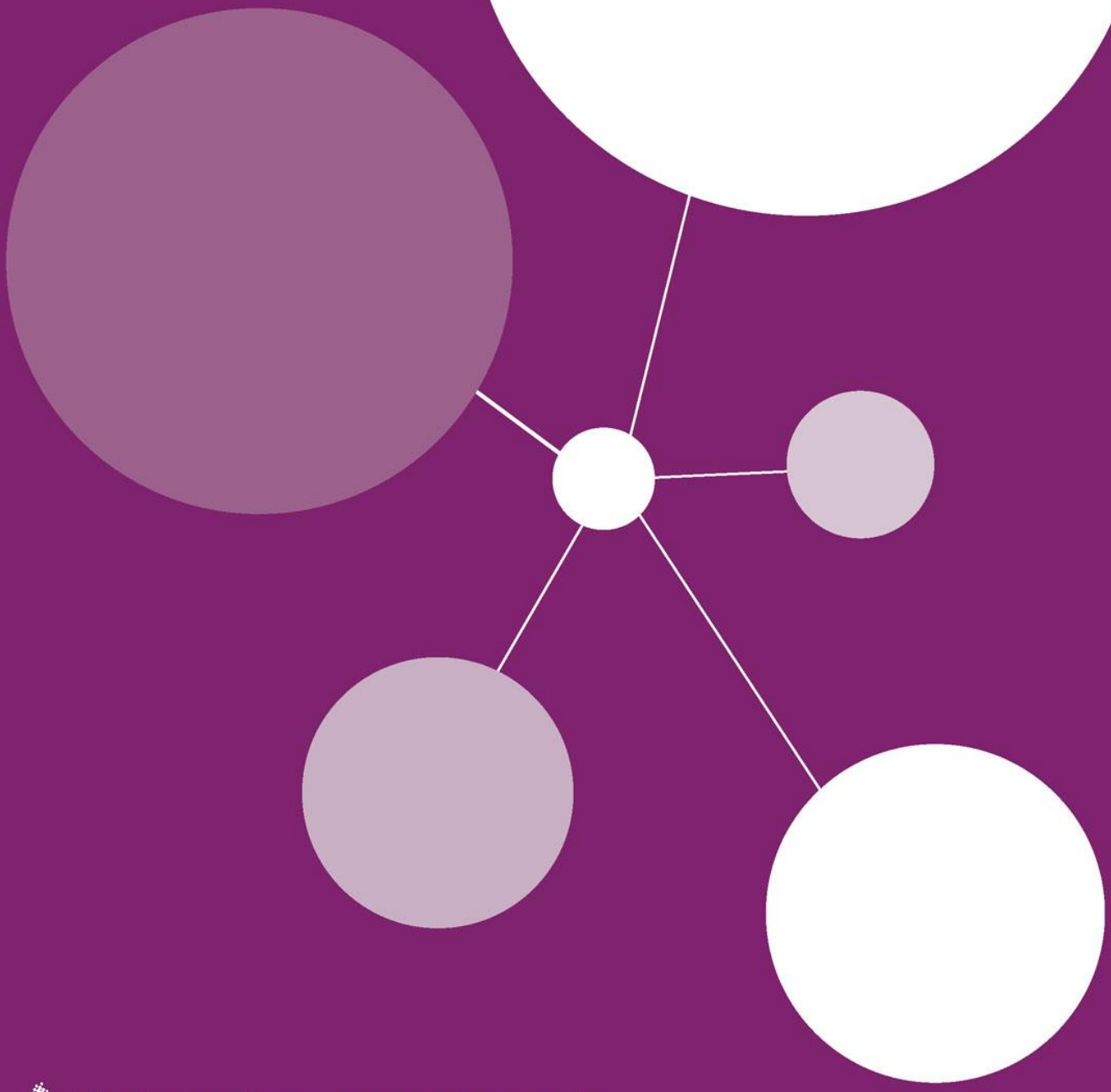
NCRI
National
Cancer
Research
Institute

NCRI Primary Care Clinical Studies Group

Annual Report 2016-17



Partners in cancer research

NCRI Primary Care CSG Annual Report 2016-17

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

The NCRI Primary Care CSG has had a successful year of activity and the three top achievements include:

1. Portfolio and accruals: As one of the principal remits of the CSG is to develop and maintain a comprehensive national portfolio of clinical trials and other well-designed studies, we are delighted that the Group are continuing to expand our portfolio and increase the number of accruals to studies. This is demonstrated by the data in Table 1 and in the Subgroup reports. What is also encouraging is the continued pipeline of studies, ensuring that we will continue to deliver on this in coming years.
2. Strategy document: One of the major achievements of the past year has been to develop and adopt, for the first time, a mature strategy document to determining the future work of the Group and its capacity to deliver its strategic aims over coming years. This has been an exceptionally useful process and will stand the CSG in good stead for the future.
3. CATALYST award: Last autumn, Cancer Research UK awarded its first CATALYST award. This £5M, five-year award in population cancer research is intended to be "paradigm-shifting" and establish new international collaborations to increase research capacity. It reflects hugely well on the work of the CSG that the inaugural award was made to the CanTest Collaborative led by Fiona Walter and Willie Hamilton (along with other present and past members of the CSG and its Subgroups). CanTest aims to develop and implement new and improved cancer diagnostic tests in primary care.

However, there are ongoing challenges for the CSG in carrying out its remit. These include:

- Ongoing difficulty in ensuring that portfolio studies are correctly allocated and that accruals are properly counted. We are working with all parties to solve this issue.
- We have yet to hold an annual trials day but are actively working towards doing so in the coming year (see Section 11). A lack of central funding is the main barrier to the Primary Care CSG in doing so.
- We have difficulty in capturing all of the required outputs for this report – especially publications and presentations. Without dedicated administrative support to do so, these lists will always be incomplete.

2. Structure of the Group

During the past year we have welcomed Professor Andrew Wardley to the CSG. Professor Paul Little has rotated off the Group and Professor Una Macleod has left to focus on her new

appointment as Dean of Hull York Medical School. Dr Helen Creedon and Dr Rosalind Adam have joined the CSG as trainees and have already made significant contributions.

3. CSG & Subgroup strategies

Main CSG

During this year, the CSG finalised its strategy document. This document will be invaluable in determining the future work of the Group and its capacity to deliver its strategic aims. The document is the result of the Strategy Day held in 2016 and participants included members of the CSG and key externally invited stakeholders. The day was facilitated by Professor 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, the Consumer Forum, the current CSG Subgroup structure, environment and portfolio, the Primary Care CSG Quinquennial Review (QQR), the funding environment, the Independent Cancer Taskforce, NHS challenges in devolved nations, the 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 have been group sessions on where the CSG saw itself in three years' time (covering: aspiration, defining and influencing the agenda and how to measure success) and developing a strategy with timelines and responsibilities by Subgroup. 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 the strategy is the result of subsequent analysis by the Chair, Subgroup Chairs and CSG members.

In future years, we will report on progress against this strategy. The Subgroup reports that follow are based upon work over the past year prior to adoption of the new strategy.

Survivorship Subgroup (Chair, Professor Eila Watson)

Key strategic aims achieved by the Subgroup for the reporting year include:

- Engagement with the Macmillan GP network and establishment of a closer working relationship.
- Engagement with the NIHR Nutrition and Cancer Collaborative – Eila Watson will represent the Subgroup as a member of the Nutritional Care for patients living with and beyond cancer research subgroup.

We have progressed our focus on recurrence research in the following ways:

- Funding of the ASICA study (Cancer Research UK) which will provide self-directed aftercare for melanoma.
- Submission of a Subgroup-initiated proposal to Macmillan Cancer Research - Symptom appraisal following primary breast cancer: promoting timely presentation to health services with possible symptoms of recurrence.
- Submission of a collaborative proposal with members of the Psychosocial Oncology & Survivorship (POS) CSG to Macmillan Cancer Support - Fears of cancer recurrence: using digital technology to aid self-management.

We have also progressed our focus on adherence to endocrine therapies research by

establishing an informal working group with members of the POS CSG and others with expertise in this area to develop a programme grant for submission in autumn 2017.

A workshop on the "Role of Primary Care Following a Diagnosis of Cancer" was convened by ourselves and colleagues from the Netherlands at the Cancer and Primary Care International network (CAPRI) conference in April 2017.

Screening Subgroup (Chair, Dr Christine Campbell)

The key activities of the Subgroup during the reporting year include:

- A mapping exercise of current UK screening activity: This was carried out by Dr Helen Creedon (trainee) and has highlighted gaps and opportunities in current screening research activity within the UK, as we consider future needs of Cancer Screening Programmes and emerging evidence for new technologies. There was supportive and enthusiastic response from colleagues on the CSGs we contacted and a fuller report is under development.
- The CSG strategic review (May 2016) highlighted a number of areas as priorities for the Subgroup to focus on: These dovetail well with the findings of the mapping exercise and are informing discussion and detailed planning (timelines and tasks) in both short and medium term planning.
- Funding applications were submitted or are in development. These include applications on ethnicity and cervical screening in Scotland, further work on interval cancers (early stage) and exploratory descriptive studies under discussion relating to breast cancer incidence and outcomes with obesity to inform larger scale studies. A number of Subgroup members are involved in a Catalyst application led by Professor Peter Sasieni.
- Engagement with NCRI CSGs: Developing collaborative working with relevant site-specific CSGs (including for areas/topics arising from the mapping exercise) remains a priority.
- Yorkshire Lung Screening Study: This primary care based study has been funded by Yorkshire Cancer Research and will recruit >14K patients in coming years.

Early Diagnosis Subgroup (Chair, Dr Fiona Walter)

Key strategic aims that have been achieved by the Subgroup during the reporting year include:

- Achieving funding for another flagship programme - the CanTest Collaborative (PIs: F Walter and W Hamilton) via CRUK's Catalyst award. This is a major investment in primary care cancer diagnostics research, capacity and education, bringing five year's funding to four UK and four international institutions.
- Achieving funding for RCTs with three currently recruiting, including the CRUK-funded BEST3 trial of the Cytosponge-TFF3 test across 120 general practices (PI: R Fitzgerald).
- Recruiting to studies across a range of cancer sites (upper GI – ECASS and POSTCARD; melanoma - MelaTools studies; myeloma - DJiM; prostate - HUMUS; lung - LUCUS; brain - BRAcED).
- Recruiting among higher risk populations (emergency presentations - EMPRESS; ethnic minorities - HUMUS; deprived communities - ABACus).
- Supporting capacity-building with three current PhD studies and four in set-up.
- Supporting and achieving funding for >14 new studies this year from a range of funders including programme support from Cancer Research Wales, study support from CRUK, Roy Castle Lung Cancer Foundation and Yorkshire Cancer Research.
- Collaborating with the Department of Health Policy Research Unit members on new studies, e.g. WELCOME-GP.

- Engaging with other CSGs to develop new applications, e.g. Prostate, Lung, Colorectal and Skin.
- Engaging with international colleagues, e.g. in Europe, North America and Australasia.

4. Task groups/Working parties

No specific task groups or working parties to report in the past year.

5. Patient recruitment summary for last 5 years

In the Primary Care CSG portfolio, 5 studies closed to recruitment and 11 opened.

Table 1 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	-	-
2016/2017*	10128	2370	9884	1315	-	-

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

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

The work of the Primary Care CSG involves collaboration with most site-specific CSGs and some of the cross-cutting CSGs. This is reflected in our portfolio. Our links with other CSGs have led to funded studies in collaboration with the Lung, Skin, Upper GI, Haematological Oncology, Prostate and Brain CSGs, and applications submitted with members of the TYA & GCT, Breast and POS CSGs.

As in previous years, we continue to develop good links with links with other CSGs but there remains a risk of our resources becoming overstretched. Three Primary Care CSG members sit on the SPED Advisory Group which has been very useful for developing proposals with other CSGs and we look forward to this continuing into the future.

International links have also increased including those through the CanTest Collaborative (Houston, Seattle, Aarhus and Melbourne).

7. 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**
May 2016			
CANDID: CANcer Diagnosis Decision rules	Full application	Professor C Ottensmeier &	Not funded

		Professor P Little	
November 2016			
A school and home-based intervention to increase cervical screening intention in mothers and daughters in deprived areas of Scotland: intervention protocol and design of a feasibility study	Full application	Dr G Hubbard et al	Not funded
Other committees			
Study	**Committee & application type**	**CI**	**Outcome**
Feasibility and acceptability of electronic cigarettes as an aid to smoking cessation for bladder cancer and head and neck cancer patients	Cancer Research UK	Jo Brett (Subgroup members co-apps)	Not funded
Knowledge, attitudes and current practice of health professionals regarding the use of e-cigarettes and other smoking cessation interventions in cancer survivors	Cancer Research UK	Jo Brett (+ Subgroup co-apps)	Funded
WICKED: Wales Interventions and Cancer Knowledge about Early Diagnosis	Cancer Research Wales Programme Grant	Professor R Neal	Funded
The role of pelvic examination in primary care in diagnosing gynaecological cancer	Chief Scientist Office	Dr P Williams, Dr P Murchie	Funded
Using qualitative methods to understand the GP/patient conversation	CRUK - EDAG	Dr K Whitaker & Dr G Black	Funded
LUSH: LUng Symptom awareness and Health	CRUK - NAEDI Project Grant	Dr K Brain	Funded
CanTest	CRUK - PRC Catalyst Award	Dr F Walter	Funded
ASICA	CRUK - PRC Project Award	Dr P Murchie	Funded
BEST3: Cluster RCT comparing the Cytosponge-TFF3 test with usual care to facilitate the diagnosis of oesophageal pre-cancer in primary care	CRUK - PRC Project Award	Professor R Fitzgerald	Funded
Decision support for cancer diagnosis in Primary Care	CRUK - PRC Project Award	Professor B Delaney	Not funded
SCAN: Suspected CANcer pathway	CRUK, Macmillan and DoH	Dr B Nicholson, F Gleason, S Hayles	Funded
WELCOME-GP: Writing to Encourage Late Consultation Outpatients to Make Engagement with their GP	DH Policy Research Unit	Professor S Duffy	Funded
Lay referral in the early diagnosis of cancer	KESS II PhD studentship	Julia Hiscock & Professor R Neal	Funded
Fears of cancer recurrence: using digital technology to aid self-management	Macmillan Cancer Support - Outline Application	Laura Ashley (joint study with POS CSG - subgroup co-apps)	Outcome pending
Improving patient-centred outcomes following a diagnosis of cancer: enhancing the role of primary care	Macmillan Cancer Support - Outline Application	Dr E Watson (+ Subgroup co-apps)	Outcome pending
Symptom appraisal following primary breast cancer: promoting timely presentation to health services with possible symptoms of recurrence	Macmillan Cancer Support - Outline application	Professor L Brindle (+ Subgroup co-apps)	Outcome pending

DIPSTICK: Improving the diagnostic process for patients with bladder and kidney cancer: how and why do missed diagnostic opportunities occur?	NIHR SPCR and Wellcome DTF awards	Dr Y Zhou, Dr F Walter, Dr G Lyratzopoulos	Funded
Safety netting and re-consultation for lung cancer symptoms: GP and patient perspectives	Roy Castle Lung Cancer Foundation	Dr G Black	Funded
ABACuS3	Yorkshire Cancer Research	Dr K Brain	Funded
Bowel Scope Screening Programme	Yorkshire Cancer Research	Dr C von Wagner	Funded
Optimise time to presentation of lung cancer symptoms	Yorkshire Cancer Research	Professor U Macleod	Funded
PEOPLE: Primary care and community engagement to optimise time to presentation with lung cancer symptoms in Hull	Yorkshire Cancer Research	Professor U Macleod	Funded
Yorkshire Lung Cancer Screening Trial	Yorkshire Cancer Research	Dr M Callister	Funded

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 for SystmOne users; the MelaTools I study is investigating GP behaviour using software integrated by EMISWeb and SystmOne and the CLASP programme also has close links with software suppliers. The CanTest Collaborative is likely to increase activity in this area.

9. Impact of CSG activities

Impact of CSG activities are outlined below:

- Many of the Group's outputs informed NICE guideline NG12 (suspected cancer: recognition and referral) which was published last year, most notably the series of paper from the DISCOVERY NIHR programme. We report this again this year as they were completed in the past five years.
- Many CSG members provide ad hoc advice to a huge range of funders and research / NHS organisations.
- Members of the CSG contributed to the NCRI Cancer Screening and role of germline genetic profiling for risk based prevention workshop.
- Richard Neal contributed to the NCRI/NHSE Older People and Cancer workshop.
- Richard Neal is a member of the Population Health Working Group.
- Richard Neal is a member of the Clinical Trials Innovation Working Group.

10. Consumer involvement

Janice Rose

This has been my third year as a consumer member of the Primary Care CSG and my mentor is Eila Watson, Chair of the Survivorship Subgroup. I feel welcomed and included equally at meetings and teleconferences by all members of the Group. This makes for a positive working environment because the members work with respect and trust for one another's ability and knowledge and I endeavour to represent the patient and carer's perspective always.

I continue to be a consumer member on the Screening and Survivorship Subgroups. I also contribute to several management and advisory groups of those projects on the Primary Care CSG's portfolio, some of which are also within the Early Diagnosis Subgroup. I am a co-applicant on funding applications, both successful and unsuccessful.

I have commented on patient information sheets and consent forms for patients and Plain English Summaries with some of the research projects that I am currently working with. I have been involved with published papers for a completed project. I comment on both the need, and the way, in which feedback might be given to those people participating in the research projects. Using some of my local and regional contacts, I support the dissemination of project results. These examples demonstrate the sort of impact that a consumer can have when working with a CSG.

I value the help that I get from the Consumer Forum, with weekly updates online, meetings during the year and also as a group of people with whom I can speak to. This support adds to my knowledge and development about cancer research and consumer involvement within it. It is also helpful having a second consumer member on the CSG with whom I can share and discuss aspects of the Group's work. I look forward to the year ahead.

Ann Russell
Since leaving the Colorectal CSG, I retained membership of the Adjuvant & Advanced Disease Subgroup and Surgical Subgroup. Last month I attended my last meeting of the former and, following the next meeting, I will leave the Surgical Subgroup in order that consumer representatives on the main Colorectal CSG can become members of these Subgroups.

During this year, I joined the Primary Care Survivorship Subgroup and have contributed to the design of an application for Macmillan funding for a study. The five year strategy has been produced and the Chair asked me to take the lead role for the strategic objective 'to consider work in nutrition'.

I have formed good working relationships with various members of the CSG and I am appreciative of the support I receive from all members and their interest in my various involvements. I am a committed advocate for the publication of all trial results, as well as the courtesy of keeping trial participants informed of outcomes. Although there is no formal arrangement for contact with my mentor, Dr Fiona Walter, her support and advice is always available. Janice Rose and I work well together in the limited time face-to-face meetings allow and we maintain contact outside the meetings on various topics.

My membership of the Consumer Forum is something I value for the wealth of experience and support this affords me. Meetings are always informative and give insights into numerous areas of research. I have successfully introduced six CSG consumer members to their counterparts in Australia and plan to report on this initiative later this year.

Activities include:

- I continue to be a consumer representative on:
  - MRC CTU
  - NIHR infrastructure collaboration 'Cancer & Nutrition' Research workstream
  - CRN – Eastern
  - CUH five year Strategic Planning Stakeholder Group

- Co-applicant for three current studies and collaborating on a further study co-producing a grant proposal regarding novel surgical techniques.
- Member of two physical exercise studies TSC's and also FOCUS4, Add Aspirin, TREK and STAR TREK TSC's.
- Continue to receive numerous requests to contribute to/review 'plain' English summaries, protocols and PIS's.
- Member of the Stakeholder group of the HTA as a representative of ICPV.

11. Open meetings/annual trials days/strategy days

Dr Rosalind Adam (trainee member) has been working closely with the Chair to investigate all the options for holding an annual trials day and we are confident that the Group will hold its first one in 2018. We have been in discussions with the Society for Academic Primary Care and the Royal College of General Practitioners regarding the possibility of having a meeting as an "add-on" to their annual scientific meetings and these discussions are going well. However, there continue to be a number of barriers to holding this in a similar way to which other CSGs hold theirs. These include:

- Issues over exactly who our constituency is: There are 50,000 GPs and their allied staff working in primary care in the UK – and all these have the potential to recruit to our portfolio studies. Hence we propose a mixed audience of 'service GPs and their staff and primary care researchers (some of whom will be GPs)
- The aims of the day: We propose that it would have to be a mix of some of the outputs from portfolio studies, studies that are currently recruiting, and studies that will shortly be coming onto the portfolio
- Financial support for the day: Unlike many site specific CSGs, we do not have natural industrial sponsors and need to look at alternative models of financial resource.

However, we are aware that there has been some relevant regional activity in the area. For example, there is a NIHR Clinical Research Network Yorkshire and Humber Joint Cancer and Primary Care meeting in June 2017.

12. Priorities and challenges for the forthcoming year

Priorities

1. Using existing (and upcoming/new) research priorities to drive our research agenda and consider a 'Priority Setting Exercise' in 12 months' time if we feel that existing documents are not giving us enough strategic direction in our work. This is articulated in items 1.2 and 1.3 of the strategy document (see Appendix 2).
2. Operationalising our strategy document to ensure that we deliver on our remit of developing and maintaining a comprehensive national portfolio of clinical trials and other well-designed studies.
3. Organising an annual trials day: We have made progress on this and expect to hold our first trials day in 2018 (see section 11).

Challenges

1. Portfolio: Whilst further progress has been made since last year's Annual Report and QQR, we continue to have some concerns that the portfolio does not properly reflect our activity.

2. Collaborative work with other CSGs: This is similar to last year in that 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.
3. Membership: In order to deliver on the strategy document, we need to co-opt or recruit members with specific remits, e.g. prevention, links with the DH Policy Research Unit. Identifying and recruiting the best people for this may be challenging.

13. Appendices

Appendix 1 - Membership of main CSG and subgroups

Appendix 2 – CSG and Subgroup strategies

Appendix 3 - Portfolio Maps

Appendix 4 - Publications in previous year

Appendix 5 - Major international presentations in previous year

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 Rosalind Adam*	Clinical Lecturer	Aberdeen
Dr Paul Brocklehurst	Clinician Scientist	Manchester
Dr Helen Creedon*	Clinical Tutor Associate	Edinburgh
Mrs Janice Rose	Consumer	Gloucester
Mrs Ann Russell	Consumer	St Neots
Professor Richard Neal (Chair)	General Practice	Leeds
Dr Fiona Walter	General Practice	Cambridge
Professor David Weller	General Practice	Edinburgh
Professor Andrew Wardley	Medical Oncologist	Manchester
Dr Thomas Round	PCRN Rep	London
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 Christine Campbell	Senior Research Fellow	Edinburgh
Dr Liz Mitchell	Senior Research Fellow	Hull/York

* denotes trainee member

Membership of the Subgroups

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

Early Diagnosis Subgroup		
Name	**Specialism**	**Location**
Mrs Margaret Johnson	Consumer	Cambridge
Dr Brian Nicholson*	Doctoral student, General Practice	Oxford
Professor Willie Hamilton	General Practice	Exeter
Professor Paul Little	General Practice	Southampton
Dr Peter Murchie	General Practice	Aberdeen
Professor Richard Neal	General Practice	Bangor
Professor Greg Rubin	General Practice	Durham
Dr Fiona Walter (Chair)	General Practice	Cambridge
Dr Suzanne Scott	Health psychology	London
Dr Katriina Whittaker	Health psychology	Guilford
Dr Yoryos Lyratzopoulos	Public Health	UCL

Screening Subgroup		
Name	**Specialism**	**Location**
Dr Helen Creedon*	Acting Consultant Oncologist	Edinburgh
Dr Paul Brocklehurt	Clinician Scientist	Manchester
Dr Sunil Dolwani	Consultant Gastroenterologist	Cardiff
Mrs Janice Rose	Consumer	Gloucester
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 Associate	London
Professor Sheina Orbell	Psychologist	Essex
Dr Anita Lim	Senior Epidemiologist	London
Dr Christine Campbell (Chair)	Senior Research Fellow	Edinburgh
Dr Rhian Gabe	Statistician	London

*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	

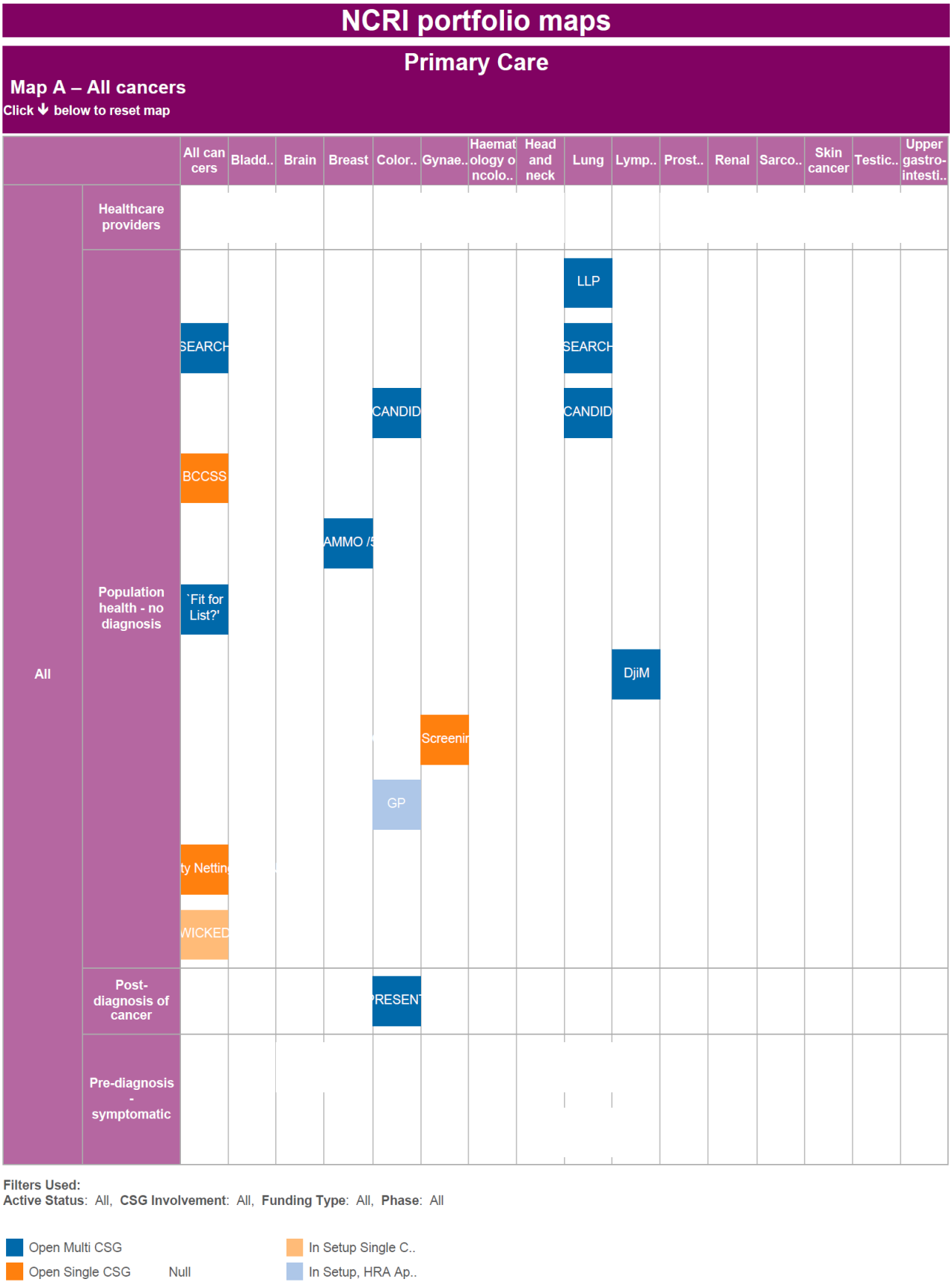
1.9	Encouraging researchers to present relevant studies at SPED	Consideration of submitting screening and ED studies for SPED workshops to improve quality, greater collaboration, and increased chances of funding	CC & SPED members (RN, FW, PM)	Annual Reports and SPED minutes	3 years – May 2020 / next 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

Publications in the reporting year

Note from Chair: We are aware that this list is incomplete but without administrative support to chase authors of all current and past portfolio studies, these are very hard to capture

Study	Reference
The impact of body vigilance on help-seeking for cancer 'alarm' symptoms: a community-based survey	Winstanley, K., Renzi, C., Friedemann Smith, C., Wardle, J., Whitaker, K.L. (2016). BMC Public Health, 16: 1172, doi: 10.1186/s12889-016-3846-7
Smokers are less likely than non-smokers to seek help for a lung cancer 'alarm' symptom	Friedemann Smith, C., Whitaker, K.L., Winstanley, K., Wardle J. (2016). Thorax. doi:10.1136/thoraxjnl-2015-208063
Unintended consequences of an 'all-clear' diagnosis on help-seeking for recurrent or new potential cancer symptoms.	Renzi, C., Whitaker, K.L., Winstanley, K., Cromme, S., Wardle, J. (2016). British Journal of General Practice, 66, e158-170, doi: 10.3399/bjgp16X683845
ELCID	Neal RD, Barham A, Bongard E, Edwards RT, Fitzgibbon J, Griffiths GO, Hamilton W, Hood K, Nelson A, Parker D, Porter C, Prout H, Roberts K, Rogers TK, Thomas-Jones E, Yeo ST, Tod A, Hurt CN. Immediate chest X-ray for patients at-risk of lung cancer presenting in primary care: randomised controlled feasibility trial. Br J Cancer, 2017, 1–10 doi: 10.1038/bjc.2016.414
SYMPTOM STUDIES/ PIVOT/ DISCOVERY PROGRAMME	Walter FM, Mills K, Mendonca S, Abel G, Basu B, Carroll N, Hamilton W, Rubin GP, Emery JD. Pancreatic cancer: a prospective cohort study of symptoms and patient factors associated with diagnostic intervals and stage at diagnosis. Lancet Gastroenterology and Hepatology 2016 4th Oct., http://dx.doi.org/10.1016/S2468-1253(16)30079-6 [epub ahead of print]
	Hollinghurst S, Banks J, Bigwood L, Walter FM, Hamilton W, Peters TJ. Using willingness-to-pay to establish patient preferences for cancer testing in primary care. BMC Med Inform Decis Mak. 2016;16:105. doi: 10.1186/s12911-016-0345-9
	Walter FM, Emery JD, Mendonca S, Hall N, Morris HC, Mills K, Dobson C, Bankhead C, Johnson M, Abel G, Rutter M, Hamilton W, Rubin GP. Symptoms and patient factors associated with longer time to diagnosis for colorectal cancer: results from a prospective cohort study. Brit J Cancer. 2016; 115(5), 533–541. doi:10.1038/bjc.2016.221.
	Moore HJ, Tariq A, Nixon C, Emery J, Hamilton W, Hoare Z, Kershenbaum A, Neal RD, Ukoumunne O, Usher-Smith J,

ECASS	Walter FM, Whyte S, Rubin G. Evaluating a Computer Aid for Assessing Stomach Symptoms (ECASS): study protocol for a multi-site phase II exploratory cluster randomised controlled trial. Trials 2016 17:184 DOI: 10.1186/s13063-016-1307-3
TOPCAT-G	Pye K, Totton N, Stuart N, Whitaker R, Morrison V, Edwards RT, Yeo ST, Timmis L, Butterworth C, Hall L, Rai T, Hoare Z, Neal RD, Wilkinson C, Leeson S. Personalised Care After Treatment for Gynaecological cancer (TOPCAT-G): a study protocol for a randomised feasibility trial. Pilot and Feasibility Studies, 2016 2:67. DOI: 10.1186/s40814-016-0108-5
ICBP 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. An investigation of routes to cancer diagnosis in 10 international jurisdictions, as part of the International Cancer Benchmarking Partnership: survey development and implementation. BMJ Open 2016;6:e009641. doi:10.1136/bmjopen-2015-009641
TOPCAT-G	Pye K, Totton N, Stuart N, Whitaker R, Morrison V, Edwards RT, Yeo ST, Timmis L, Butterworth C, Hall L, Rai T, Hoare Z, Neal RD, Wilkinson C, Leeson S. Personalised Care After Treatment for Gynaecological cancer (TOPCAT-G): a study protocol for a randomised feasibility trial. Pilot and Feasibility Studies, 2016 2:67. DOI: 10.1186/s40814-016-0108-5
BEST3	Freeman M, Offman J, Walter FM, Sasieni P, Smith SG. Acceptability of the Cytosponge procedure for detecting Barrett's oesophagus: A qualitative study. BMJ Open, 2017;7(3):e013901. doi: 10.1136/bmjopen-2016-013901.
	Paterson AL, Lao-Sirieix P, O'Donovan M, Debiram-Beecham I, di Pietro M, Miramedi A, Attwood SE, Walter FM, Sasieni PD, Fitzgerald RC, BEST and BEST2 study groups. Range of pathologies diagnosed using a minimally invasive capsule sponge to evaluate patients with reflux symptoms. Histopathology. 2017;70(2):203-210. doi: 10.1111/his.13039.
LAPCD Study	Downing A, Wright P, Wagland R, Watson E, Kearney T, Mottram R, Allen M, Cairnduff V, McSorley O, Butcher H, Hounsome L, Donnelly C, Selby P, Kind P, Cross W, Catto JW, Huws D, Brewster DH, McNair E, Matheson L, Rivas C, Nayoan J, Horton M, Corner J, Verne J, Gavin A, Glaser AW. Life after prostate cancer diagnosis: protocol for a UK-wide patient-reported outcomes study. BMJ Open. 2016 Dec 7;6(12):e013555. doi: 10.1136/bmjopen-2016-013555

Appendix 5

Major international presentations in the reporting year

Note from Chair: We are aware that this list is very incomplete but without administrative support to chase authors of all current and past portfolio studies, these are very hard to capture

Study	Conference details
'Cancer Diagnosis' session	1st European Diagnostic Error in Medicine Conference, Rotterdam, Netherlands, June 2016
The impact of body vigilance on symptomatic presentation	Oral presentation. Cancer and Primary Care research International Network (Ca-PRI), Boston, Massachusetts, April 2016
ICBP 4	Presentation at the CRUK Early Diagnosis Conference, February 2017
SYMPTOM STUDIES/ PIVOT/ DISCOVERY PROGRAMME	UICC - World Cancer Congress, 31 October - 3 November, Paris
	Evolving Role of Primary Care in Cancer conference, VCCC, Australia
	Society for Medical Decision Making, 16th Biennial European Conference, London, June 2016
MELATOOLS	UICC - World Cancer Congress, 31 October - 3 November, Paris
	Evolving Role of Primary Care in Cancer conference, VCCC, Australia
DJiM	CRUK Early Diagnosis Conference, February 2017
Why do some smokers	CRUK Early Diagnosis Conference, February 2017