

NCRI Primary Care Clinical Studies Development Group

This has been another year of significant progress for the Primary Care Clinical Studies Development Group (CCSDG). We were established in early 2003 and in January 2006 we had our 3 yearly progress review.

Originally the Group was established partly through an acknowledgement that primary care has a growing role in all stages of the cancer journey and also because it was recognised that there was a need to increase the volume of primary care research. Our activity has focused mainly on capacity building, and we now have a growing portfolio of studies. Our review has provided us with important directions for the next period – this planning process will be further enhanced by a ‘Planning Retreat’ in Birmingham in September 2006.

Membership and structure

When the Group was originally recruited we sought membership from a wide range of backgrounds. It was drawn from academic GPs, nurses, psychologists and researchers with a wide range of expertise in both qualitative and quantitative methods. We ensured we had members who had statistical expertise relevant to clinical trial design and representation from clinical trial units. The structure of the group reflected our aim to build capacity in our field by fostering the development of multi-centre studies and to promote widespread collaboration between the primary care and cancer research community and other cancer research colleagues.

An important recommendation from our 3-year review was to broaden our membership and encourage new, younger researchers to join and to include individuals from “outside the traditional family” e.g. dentists, members of a PCT, health economists and younger junior people just beginning a research career.

To this end we have so far recruited:

- Eila Watson (senior GP researcher, Oxford Dept Primary Care)
- Dr Kerenza Hood (Dept General Practice Cardiff)
- Amanda Farrin – Statistician (replacing Julia Brown who has taken up chairmanship of Psychosocial CSDG)

We also have a second consumer representative (Diana Robinson). We will continue to seek out new members with the specific skills and disciplines identified in our review.

Planning retreat

Our review recommended holding an away day with external input to develop a three year strategy. Planning for this is now well advanced. It will be chaired by Bob Haward, and we have recruited several key resource people to help us plan our research in the context of a changing environment. It will include perspectives of UKCRN, UKPCRN, NIH, NCRI, National School for Primary Care Research and other key groupings

Portfolio and accrual

The Group are involved in a number of studies (see table below), only one of which is currently in the NCRN portfolio and two have recently been funded by PBSC and are likely to be included in the portfolio.

Our review encouraged us to continue to develop studies within our existing subgroup structure, and to have a further one or two ‘flagship’ studies developed by

the Group and successfully funded within the next year. This is a major focus of our current activity.

Studies members are involved in:

Title	PI(s)	Status
Achieving earlier diagnosis of symptomatic colorectal cancer in general practice – pilot study in 5 UK regions.	J Austoker	Pilot, will close in mid-June (113)
PICT study -tackling inequalities in the management of colorectal cancer.	N Campbell	Pilot (37)
TIME study -time to diagnosis of lung cancer.	N Campbell	Closed (362)
A prospective study to assess the value of MMP-9 in improving the appropriateness of urgent referrals for colorectal cancer. *	S Wilson	Closed (1004)
Assessing the accuracy of serum MMP-9.	S Wilson	(164)
Self test kits for cancer: Prevalence of use, characteristics of users and implications of self-testing for health care services - a feasibility study.	S Wilson	Closed (2900)
Understanding Colposcopy.	S Wilson	Qualitative phase (4)
Strategies to increase colorectal cancer screening uptake in primary care.	D Weller	Pre-recruitment phase (0)
Colorectal Diagnosis Clinical Predictor study	T Fahey	Open
FACS: A randomised controlled trial to assess the cost-effectiveness of intensive versus no scheduled follow-up in patients who have undergone resection for colorectal cancer with curative intent.	J Primrose, D Mant	Open
Prostate cancer follow-up. **	N Campbell	Approved June 2006
Assessing the potential for earlier detection of colorectal cancer in primary care, using the GP research database. **	W Hamilton	Approved June 2006
Total		4584

-Patients recruited are in brackets

* In NCRN portfolio

** Approved at PBSC June 2006

While we can't discuss all of our studies in this report, some specific issues are highlighted below:

1. Achieving earlier diagnosis of symptomatic colorectal cancer in general practice – pilot study in 5 UK regions (Funder - Department of Health)

This project has brought together researchers from 5 academic departments, and has been developed directly by the PCCSDG. It builds on previous work in this field, and addresses important practice and policy needs. Pilot DH funding is a demonstration of the policy significance attached to this work. The pilot is now complete and we are proceeding to a full application for a multi-centre study

2. Prostate cancer follow-up: Examining the role of primary care in follow-up of prostate cancer - what is being done, is it effective, and what do patients want?

This was developed by the Follow-Up Sub-group, and was funded in June 2006 by the *Cancer Research UK Population and Behavioural Sciences Committee*. The aim of study is to develop and trial interventions that will support primary care in the delivery of optimal follow up care of men with prostate cancer.

3. Breast cancer follow up: a pilot study for a randomised controlled trial of primary care based, nurse-led follow up

While this study wasn't funded by CR-UK, we received constructive feedback and are developing a re-submission in conjunction with the Breast and Psychosocial CSGs.

Our 3 year review highlighted the important issues which need to be addressed in our new application development. It's vital that we fully engage in all of the network and other support structures available (primary care has done this to a lesser extent than some of the tumour-specific CSGs). There have been many new developments such as the establishment of a UKPCRN, and we need to ensure that our research development efforts are well-integrated with these new structures.

We are looking not only for major 'flagship' studies, but also studies that bundle different types of cancer together to increase the feasibility of conducting studies in primary care (given that cancer is rare in primary care populations, and we often struggle to design studies with sufficient sample sizes). Our regular meetings provide opportunities not only for discussion of existing draft proposals, but for scoping of new research ideas. They continue to be our major driver for new applications. Increasingly members of the Group are bringing along study applications to the six monthly meetings for consideration and input from members. We also have well established mechanisms whereby we can circulate developing applications electronically.

Subgroups

We will continue with our current subgroup structure. The 3 subgroups meet regularly, either through face-to-face meetings or teleconferences. Current topics for application development being discussed by the subgroups include:

Cancer Prevention: biological and behavioural approaches Subgroup

- Use of HPV screening for cervical cancer
- Promoting informed choice in cancer screening
- Tobacco-control study

Early Diagnosis Subgroup

- Assessing delays in diagnosis of ovarian cancer:
- Early diagnosis of lung cancer.
- Early CRC diagnosis study (Pilot completed, full application in preparation)

Follow-up Subgroup

- Re-submission of breast ca proposal
- A melanoma follow-up study

A Primary Palliative Care Subgroup was established this year. Although it is hosted by the Palliative Care CSDG, it has joint chairs (one from the Primary Care CSDG and one from the Palliative Care CSDG). It includes membership from both the Primary and Palliative Care CSDGs. It has met twice and is making excellent progress in proposal development. A more complete account of this Subgroup's activity will appear in next year's report.

Links and Collaboration

The Group has continued over the last year to raise awareness of cancer research among primary care research community. Important mechanisms for links include cross representation, reports and collaborative research. We have continued to develop good links with other clinical studies groups including those in breast, colorectal, urological and lung cancer. We've stayed closely involved with central issues at NCRI and NCRN through participation in CSG Chairs' meetings and representation on other groups. We have, of course, good links with key primary care research organisations including The Society for Academic Primary Care, the Royal College of General Practitioners and the Federation of Primary Care Research Networks and with international groups including the North American Primary Care Research Group and various cancer organisations in Europe, North America and Australasia. In keeping with the recommendations of our 3 year review, we are continuing to develop further links and develop clear dissemination pathways. Over the next 12 months we will make it a priority to review links with the Royal Academies and discuss whether or not these can be further strengthened in order to develop capacity. We have a strong presence at the NCRI Conference in Birmingham in October 2006, and this will be a further opportunity for building collaborative activity.

International activity

We have formed an International Primary Care Cancer Research Group, the aim of which is to develop better links with international colleagues, develop collaborative research and to hold international scientific meetings – to this end planning is underway to hold a meeting in October 2007 (planning committee includes Kevin Oeffinger, Memorial Sloan-Kettering, NY and Eva Grunfeld, Cancer Care Nova Scotia)

Strategy for 2006/2007 and beyond

Our principle goal remains to develop capacity in our field and to build links with the wider cancer research community. As detailed in our review, we see several important strategic opportunities emerging in the future. There remains a strong interest in early primary care based diagnosis and we intend to pursue this in lung, ovarian and other cancers in collaboration with the appropriate clinical studies groups. Follow up is likely to remain a topical area and go beyond breast and prostate; melanoma and perhaps gynaecological cancer present further opportunities in this field. We maintain a strong interest in biomarkers and are intrigued by the possibilities for further early diagnostic work and combining predictivity estimates associated with biomarkers with those associated with symptoms and symptom complexes. We see new opportunities emerging in behavioural/primary prevention research, particularly with the addition of individuals such as Professor Teresa Marteau to the Group.

Our planning retreat in September will be an important opportunity to review the Group's approach to its tasks and to examine opportunities and threats relating

specifically to primary care and cancer research, and identify ways of building research capacity in our field.

Professor David Weller, Chair

Appendix 1: Key strengths and issues from the Progress Review, January 2006

Strengths:

- Doing a good job given the background and resources available
- Clear understanding of the context in which they work
- Making some interesting and excellent choices e.g. research into diagnosis
- Developing some interesting studies in colorectal cancer and biomarkers and lung cancer and biomarkers
- Working well with a number of tumour specific CSGs
- Current thinking on communication and behavioural studies

The Primary Care CSDG needs to consider:

- Having one or two flagship studies developed by the Group and successfully funded within the next year
- Studies that bundle different types of cancer together to increase the feasibility of conducting studies in primary care
- Developing a study on tobacco use
- Holding an away day with external input to develop a three year strategy
- Widening the membership to include someone from “ outside the traditional family” e.g. dentists, members of a PCT, health economists and younger junior people just beginning a research career.
- The role that the subgroups can play in developing the Groups’ agenda and developing the next generation of researchers
- Developing further links with other CSGs and CSDGs
- Developing international links
- Establishing a clear and firm relationship with the new UK Primary Care Research Network and other groups and developing clear dissemination pathways
- Reviewing links with the Royal Academies and discussing whether or not these can be further strengthened in order to develop capacity