‘Early Days Yet’
The Primary Care Cancer Lead Clinician (PCCL) Initiative

Final Report

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EXECUTIVE SUMMARY

The Department of Health/Macmillan PCCL initiative provided three years of central funding and support to enable each PCT to have a primary care cancer lead clinician for at least one session a week. The role was aimed at providing strategic leadership within the PCT, contributing to the development of Cancer Networks, improving communication between sectors, raising standards of cancer care and ensuring services are responsive to the needs of people affected by cancer. An evaluation of the project has now been completed and this note summarises the Key Findings and Recommendations.

1. Key Findings

Impact:

- Key achievements identified by PCCLs were in the areas of: communication, establishing relationships and raising awareness of cancer in primary care; setting up, membership of and chairing cancer specific groups; Baseline Assessment; palliative care and the Gold Standards Framework; out of hours services; monitoring two week referrals; local service developments.
- Despite the extensive job description, most PCCLs felt they were having an impact and wanted the scheme to continue in some form.
- There has been a major focus on palliative care, as is entirely appropriate. However, over time the emphasis should move to other neglected areas of primary care cancer.

Characteristics:

- The person in post does not have to be a GP but, whatever their background, must have the confidence of their colleagues.
- PCCLs must be people who want to be there. This is important for the next phase of the scheme where the informal knowledge and expertise accumulated by the PCCLs should not be lost.
- Being interested in cancer is not enough in itself. What is crucial is a capacity for strategic thinking with regard to service integration and development across the primary/secondary interface.
- The requirements for PCCLs are: seniority/credibility, contacts and interest, ability in communication and strategic planning.
- Recruitment was not always based on appropriate criteria. Many PCCLs were not formally appointed but simply ‘fell into the role’. Any future programme should ensure formal requirements on which the competencies of the candidates are judged.

The Role:

- As there is little clarity about the boundaries of the role, much depends on the individual. This has advantages (for those with flair and imagination) and disadvantages (for those who are inexperienced). The latter may, however, grow into the role.

- The role is more about integration than assertiveness. Where cancer is recognised as a priority, PCCLs do not have to be particularly assertive.
- PCCLs were introduced at a time of change for Primary Care Trusts (PCTs). Developing and improving relationships were initial prerequisites for many PCCLs before they could move on to develop their role further.

Support:

- Many PCTs, Cancer Networks and Acute Sector clinicians appeared to know little about the initiative, and some are still unaware. This added another unnecessary dimension of uncertainty for PCCLs which might have been avoided.
- A recognisable presence in the PCT, either by being a Professional Executive Committee (PEC) member, by being invited to the PEC for specific items or to give a presentation, was regarded as an essential prerequisite to raising the profile of cancer in primary care.
- Support from the PCT, Cancer Network and Acute Sector is essential for PCCLs to be able to make an impact. The role is most effective where there is a co-ordinated structure of decision-making and implementation.
- Additional back up support in the form of secretarial, administrative or managerial assistance at PCT level would greatly assist the PCCLs in the pursuit of their goals.
- Specific dedicated funding from the PCTs is essential if PCCLs are to continue to fulfil their role successfully.
- Although lack of time was a major constraint, this could be alleviated by prioritising the remit of the PCCLs more clearly.

The Macmillan Support Programme:

- The Macmillan Support Programme was highly regarded by those who used it, primarily as a place to discuss successes/challenges with peers.
- The Macmillan Support Programme was essential, at least initially, since many PCCLs had no idea what was expected of them.
- Although not perfect, many PCCLs would have floundered without the Macmillan Support Programme.
- Support for PCCLs new to the role was essential, but was needed less over time as PCCLs ‘grew into their role’. It may still be needed in some format for incoming PCCLs.

The Future:

- Most PCCLs wanted the role to continue so that they can continue to develop strategy and improve cancer services in primary care.
- It is still ‘early days’. The next two years should show major improvements in primary care cancer as a result of PCCL input.
- In areas where recruitment has been difficult, innovative ways of providing PCCL services need to be tested to ensure that inequalities are not perpetuated.
- The new GMS contract could provide PCCLs with a route into practices in those areas where this has proved difficult.

2. Recommendations

Recommendation 1: The PCCL role should continue. This might be in different formats in different areas.
Recommendation 2: Innovative ways of providing PCCL input, tailored to local circumstances, should be considered in areas with specific problems.
Recommendation 3: PCTs with recruitment problems, where the PCCL role has been taken on by existing staff, should carefully examine their resource input to ensure workloads are equitable.
Recommendation 4: Consideration should be given to prioritisation of the PCCL Job Description to make the role more manageable.
Recommendation 5: Consideration should be given to making the PCCL role more widely understood at all levels. This could be an activity for PCTs, Networks or for Macmillan.
Recommendation 6: Consideration should be given by PCTs as to whether the practical support they provide to their PCCLs requires reassessment.
Recommendation 7: Networks should consider ways in which they can provide more support to PCCLs by lowering the barriers to active participation.
Recommendation 8: The PCCL remit should incorporate all aspects of primary care cancer.
Recommendation 9: PCCLs and PCT managers should consider the opportunities of the new GMS contract and the contribution that PCCLs might make.
Recommendation 10: The significance of the strategic nature of the PCCL role should be emphasised, perhaps via the Macmillan Support Programme.
Recommendation 11: Care should be taken at all levels to ensure that informal knowledge accumulated by PCCLs is not lost.
Recommendation 12: Ongoing background and mutual support for PCCLs is still essential, particularly for those new to the role. The Macmillan Support Programme is already planning to continue this support.
Recommendation 13: PCTs should continue to fund PCCLs.

3. Background

The NHS Cancer Plan described the need to improve cancer services in the community. PCTs have responsibility to develop services in primary care and commission other services. They are, therefore, regarded as important in offering new opportunities to improve and shape the delivery of cancer services for patients in the community, especially through their involvement in the Cancer Networks. The Calman Hine Report recommended setting up networks for cancer care, extending from primary care to cancer units in the secondary sector and for tertiary care. Cancer Networks were identified in the NHS Cancer Plan as the organisational model for cancer services to implement the Cancer Plan. The objectives of the Networks are to ensure that all commissioners and providers of health care, the non-statutory sector and local authorities within the Cancer Network work effectively together to deliver high quality care. The introduction of PCCLs in each PCT was aimed at involving primary care professionals in the Cancer Networks, and providing them with the opportunity to contribute to Network development. In addition, PCCLs would raise standards of care within their PCTs and improve communication and understanding across primary, secondary and tertiary care. One milestone was set that by 2001, all PCTs should appoint a PCCL. The Department of Health, in partnership with Macmillan Cancer Relief, has provided funding to support the introduction of this role nationally. They have also funded this evaluation to assess the impact of the PCCL role to inform decisions about how the role should develop in the future.

4. Aims and Objectives

The aim of the study was to evaluate whether or not the nomination of a lead clinician at PCT level for cancer (the Primary Care Cancer Lead Clinician or PCCL) in the primary care setting, with a defined role description, dedicated time and a personal support programme accelerates the achievement of national and local service improvement targets through demonstrable and measurable change processes.

The objectives were:

1. To examine the extent and nature of PCTs' use of PCCLs
2. To examine the level of national and local service improvements attributable to the PCCLs
3. To explore progress on the five strategic elements of the PCCL Job Description
4. To identify characteristics of PCCLs that have ensured their effectiveness, and how these change over time
5. To examine the impact of the PCCLs' clinical background on how they perform their role
6. To identify the factors associated with the successful achievement of the PCCL role
7. To examine the impact of relations with PCTs, Cancer Networks and local GPs on the PCCL role
8. To examine the impact of the Macmillan Support Programme on PCCL effectiveness and identification of any changes that might be required
9. To identify and quantify the costs of providing PCCL services
10. To identify how the PCCL role might develop in the future and to make recommendations.

Using measures of structure, process and (where available) outcome, the study was designed to evaluate the effectiveness, efficiency and costs of PCCL schemes and identify issues that need to be changed in the future.

5. Methods

This study was conducted between 1 June 2003 and 31 March 2004 (10 months) and consisted of four phases. Phase 1 was a national postal survey of PCCLs and Chief Executives (or their substitutes) in all PCTs in England. Phase 2 consisted of case studies in six sites based on Cancer Networks including telephone interviews with key informants. Due to the short time scale available for the study, Phase 2 partly overlapped with Phase 1. Phase 3 also ran concurrently with Phase 2 and consisted of collecting the views of the Macmillan Support Programme Providers. Phase 4 was a period for finalising data analysis, writing up the Final Report and making Recommendations.

6. Discussion and Conclusions

The Discussion is centred around the Objectives of the study. Each Objective is set out below as a heading and the relevant points from the study findings are collected together so providing a summary of the main study Conclusions.

1. To examine the extent and nature of PCTs' use of PCCLs:

- In a supportive environment – with access to facilities such as secretarial, administrative and/or managerial support – so much more can be achieved since PCCLs need to spend much less of their time in building up relationships within and outwith the PCT. Essentially, they had a head start.
- PCCLs spend a large part of their time attending meetings at all levels, both within the PCT and elsewhere. This can be seen as a reflection of their strategic role - receiving and passing on information about cancer services and their development, making themselves more widely known and promoting the cause of primary care cancer.
- Those who were on the PEC felt that it was helpful to their cause. Others, however, noted that being on the PEC in a tokenistic manner and not being listened to was even worse. Some of those not on the PEC, who had no desire to be so, tended to be those whose status was assured in the PCT and more widely in the local health economy. For them, being on the PEC was irrelevant.
- Ways in which PCCLs had contributed to the PCT were in acting in an advisory capacity, in forward planning, developing cancer care pathways and commissioning and audit. The aspect of cancer care that PCCLs had overwhelmingly concentrated on was palliative care and the Gold Standards Framework (GSF).
- One way forward would be to embed the PCCL role more closely with PCT management and support infrastructure, as well as sharpening the focus of the remit to promote clarity and avoid overlap with others with a cancer remit in the PCT.

2. To examine the level of national and local service improvements attributable to the PCCLs:

- As mentioned above, PCCLs were focusing predominantly on palliative care. Other areas of focus were improving communication and early diagnosis and referral, and these were the areas that the PCCLs also thought that they had the most impact on.
- Most PCCLs did think that they had contributed to raising standards of care and hence contributing to service improvements, by means of raising the profile of primary care cancer at all levels. This had led to improvements to palliative care services, shorter waits and improved communication at all levels.
- PCCLs can find it problematic to influence strategy and raise standards, as can be seen with the difficulties experienced in engaging GP practices in Baseline Assessment.

3.To explore progress on the five strategic elements of the PCCL Job Description:
The five strategic elements are identified in bold below.

1. ***To provide strategic leadership within the PCO in line with the NHS Cancer Plan to develop services for cancer patients:***

- Although PCTs were encouraged to add to the single session per week funded by the Department of Health, most did not do so. PCCLs, therefore, had only 3-4 hours of funded time per week available to them and cannot achieve everything in such a large remit.

- Success in Baseline Assessment was identified as one of the key achievements of the PCCLs.
- There was some concern about the quality of the baseline data from practices: it was of variable quality and frequently under-developed.
- Prevention and screening strategies did not feature highly, but this may change in the future.
- Progress with 'two week waits' was one of the PCCLs' key achievements.

2. ***To contribute to the development of Network service delivery plans in order to streamline patient care (using the 'care pathway' approach):***

- Most PCCLs attended Network meetings.
- Palliative care and patient care pathways were important aspects of the PCCL role. There was significant input into this aspect of primary care cancer.
- Cancer services commissioning was being focused on by PCCLs, but at a much lower level than palliative care, early diagnosis and referral. Some had found it difficult to get involved in commissioning.

3. ***To contribute to Network development and, where appropriate, to represent the PCO and primary care in the Cancer Network:***

- Most PCCLs represented their Primary Care Organisation (PCO) and primary care at Network level.
- Raising awareness of primary care cancer was identified by PCCLs as one of their key achievements, at Network level and elsewhere.

4. ***To raise standards of cancer care within the PCO in collaboration with the clinical governance lead:***

- PCCLs attached some importance to working with the PCT clinical governance lead.
- Many PCCLs felt they had raised the standard of cancer care in their PCT, as did the PCT managers, primarily by raising awareness of primary care's contribution to cancer care, and by their promotion of palliative care and GSF.
- Establishment of cancer datasets was problematic because of lack of engagement by many GPs.

5. ***To ensure that services are responsive to the needs of people affected by cancer:***

- Many PCCLs have made contact with local user groups and others had plans in place to do so.
- Awareness of all aspects of the Macmillan Support Programme (which included frequent references to, and specific information and resources about, how to involve people affected by cancer in the design and development of services) was almost universal amongst PCCLs.
- Attendance at Collective Learning Set (CLS) events (where learning was often shared concerning how best to involve people affected by cancer in the design and development of services) averaged 50-60%.

In summary, the PCCLs had made considerable inroads into many aspects of the Job Description.

4.To identify characteristics of PCCLs that have ensured their effectiveness, and how these change over time:

- The most important personal attributes that PCCLs identified were communication skills, enthusiasm, knowledge and persistence, as well as good relationships with colleagues. These were closely paralleled by the views of the PCT managers.
- Ensuring key individuals were aware of the post and its intentions would be of considerable help in allowing PCCLs to move forward without having to first explain themselves, and would facilitate the building of relationships. It is this that has so occupied many PCCLs in their early years and meant that their real work of developing strategy had been limited.
- Those who had previous experience, perhaps in commissioning or as PEC Chair, and were used to thinking strategically appear to have particularly enjoyed the role, emphasising further the significance of the ability to take a strategic viewpoint.
- Three years is not long, and is even shorter if much time is taken up in building relationships. Local knowledge, credibility and the ability to take a strategic standpoint are significant in allowing PCCLs to move forward quickly.

5.To examine the impact of the PCCLs' clinical background on how they perform their role:

- Whether the PCCL is a GP, Nurse or other health professional is less important than having credibility with their colleagues and the support of the PCT.

6.To identify the factors associated with the successful achievement of the PCCL role:

- Key achievements were associated with developing relationships locally and raising awareness of primary care cancer. These are the sorts of achievements to be expected in the early phases of a new initiative.
- Other achievements were more specifically task orientated, including progress with Baseline Assessment, out of hours, palliative care and two week waits. These achievements were also those identified by PCT managers except that the placed greater emphasis on palliative care.
- The factors associated with key achievements included prior knowledge of the local health economy, which enabled the initial phase of building relationships to proceed more quickly; and local credibility, which again acted in a facilitation capacity.
- Those who had identifiable support at PCT, Cancer Network, and from the Macmillan Support Programme found their role much easier to fulfil.
- Some PCCLs thought that PEC membership was important, although this was not shared by PCT managers.
- Dedicated funded time was also seen as essential to the achievement of the role, coupled with the personal skills of the post holder – in particular their commitment, determination and personal application.

- There could be a lack of awareness at all levels of what the PCCL role entailed, and a lack of communication with the PCT, Cancer Network and secondary care.
- Lack of time was a universal complaint, reflecting the extensive nature of the PCCL job description. However, time might not be a factor if the requirements of the post were channelled appropriately instead of having to attempt to fulfil the entire remit.

7.To examine the impact of relations with PCTs, Cancer Networks and local GPs on the PCCL role:

- Support was key to PCCLs. Many did receive support from their PCTs, although a minority did not, with some dissatisfaction being expressed.
- A high level of support to the PCCLs who were GPs came from their own practices.
- Macmillan was also seen as supportive.
- Local GPs and nurses were described as much less supportive - even obstructive - making Baseline Assessment particularly difficult.
- Contact and collaboration with key individuals was extremely important to PCCLs, particularly with the Network, hospice, the palliative care lead, secondary care clinicians and commissioning managers.
- Over three quarters of PCCLs represented their PCT at Network meetings and two thirds had helped to develop service delivery plans.

8.To examine the impact of the Macmillan Support Programme on PCCL effectiveness and identification of any changes that might be required:

- A well-designed curriculum was put together by Macmillan Cancer Relief which exhibited considerable foresight in anticipating PCCL educational and support requirements.
- For those PCCLs who used it, the Macmillan Support Programme Collective Learning Sets (CLSs) were highly regarded as a place to discuss successes and problems with peers. This was essential, at least initially, because many PCCLs had little idea of what was expected of them.
- However, despite the enthusiasm for CLSs exhibited throughout this Report, attendance rates were not always particularly high.
- Although most PCCLs had heard of all the aspects of the programme, the use that was made of the different parts varied considerably, with the website being particularly under-utilised.
- The Macmillan Support Programme had a very significant impact on the effectiveness of those PCCLs who used it, especially the CLS. PCCLs particularly rated improvements in their knowledge and collaborative abilities. They attributed improvements in their influencing and negotiating abilities to the Macmillan Support Programme. Despite this, a number of PCCLs were unable to attribute any of their skills improvements to the programme, although for some, it was still early days.
- The Macmillan Support Programme is probably of greatest support to PCCLs who are not on the PEC, to help ensure they do not feel too isolated.

9.To identify and quantify the costs of providing PCCL services:

- The costs of the PCCL initiative have, until 31 March 2004, been borne by the Department of Health with Macmillan Cancer Relief providing the associated support programme.
- Subsequently, PCTs will have to decide whether the role should continue, and provide funding if it does.
- Currently, funding is between £7000-£10000 per PCT per year to support the role for one session per week. It has been estimated that £2000 of additional support has been provided by PCTs and this would be required to sustain the initiative at its current level.
- In many PCTs, however, PCCLs would benefit from additional resources.
- This cost is minimal in relation to PCT total budgets.
- A commitment from PCTs to continue to fund PCCLs, and even to extend the scheme, is likely to provide major benefits in the next two years.

10.To identify how the PCCL role might develop in the future and to make recommendations:

- There was almost universal support from the PCCLs and the PCT managers that the PCCL role should continue.
- How it might develop in the future, and the recommendations arising from this Report are set out in Section 2 of this Executive Summary.

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Key Findings

This Section repeats the Key Findings in the Executive Summary but also includes links to the relevant Sections in the Main Report and to the Objectives.

Impact:

- Key achievements identified by PCCLs were in the areas of: communication, establishing relationships and raising awareness of cancer in primary care; setting up, membership of and chairing cancer specific groups; Baseline Assessment; palliative care and the Gold Standards Framework; out of hours services; monitoring two week referrals; local service developments. **(Sections 4.3, 7.4, 8.6: *Objective 6*).**
- Despite the extensive job description, most PCCLs felt they were having an impact and wanted the scheme to continue in some form. **(Sections 4.4, 4.9: *Objective 7*).**
- There has been a major focus on palliative care, as is entirely appropriate. However, over time the emphasis should move to other neglected areas of primary care cancer. **(Section 4.4; *Objective 2*).**

Characteristics:

- The person in post does not have to be a GP but, whatever their background, must have the confidence of their colleagues**. (Sections 4.3, 7.6, 8.5: *Objective 5*).**
- PCCLs must be people who want to be there. This is important for the next phase of the scheme where the informal knowledge and expertise accumulated by the PCCLs should not be lost. **(Sections 6.2, 7.2: *Objectives 4,6*).**
- Being interested in cancer is not enough in itself. What is crucial is a capacity for strategic thinking with regard to service integration and development across the primary/secondary interface. **(Sections 4.11, 7.3, 7.7: *Objectives 4,6*).**
- The requirements for PCCLs are: seniority/credibility, contacts and interest, ability in communication and strategic planning. **(Sections 4.7, 4.15: *Objective 4*).**
- Recruitment was not always based on appropriate criteria. Many PCCLs were not formally appointed but simply 'fell into the role'. Any future programme should ensure formal requirements on which the competencies of the candidates are judged. **(Section 7.2: *Objective 4*).**

The Role:

- As there is little clarity about the boundaries of the role, much depends on the individual. This has advantages (for those with flair and imagination) and disadvantages (for those who are inexperienced). The latter may, however, grow into the role. **(Sections 4.7, 4.15, 7.3: *Objectives 4,6*).**
- The role is more about integration than assertiveness. Where cancer is recognised as a priority, PCCLs do not have to be particularly assertive. **(Sections 7.4, 8.4: *Objective 1*).**
- PCCLs were introduced at a time of change for PCTs. Developing and improving relationships were initial prerequisites for many PCCLs before they

could move on to develop their role further. **(Sections 4.3, 4.13, 6.3: *Objective 1*).**

Support:

- Many PCTs, Cancer Networks and Acute Sector clinicians appeared to know little about the initiative, and some are still unaware. This added another unnecessary dimension of uncertainty for PCCLs which might have been avoided. **(Sections 4.3, 4.5, 4.13: *Objective 7*).**
- A recognisable presence in the PCT, either by being a PEC member, by being invited to the PEC for specific items or to give a presentation, was regarded as an essential prerequisite to raising the profile of cancer in primary care. **(Sections 4.3, 4.13, 6.2, 7.4, 8.4, 8.6: *Objective 1*).**
- Support from the PCT, Cancer Network and Acute Sector is essential for PCCLs to be able to make an impact. The role is most effective where there is a co-ordinated structure of decision-making and implementation. **(Sections 4.3, 4.5, 4.6, 4.13, 7.4, 8.7: *Objective 7*).**
- Additional back up support in the form of secretarial, administrative or managerial assistance at PCT level would greatly assist the PCCLs in the pursuit of their goals. **(Sections 4.3, 5, 7.4: *Objective 1*).**
- Specific dedicated funding from the PCTs is essential if PCCLs are to continue to fulfil their role successfully. (**Sections 7, 8.9: *Objective 9*).**
- Although lack of time was a major constraint, this could be alleviated by prioritising the remit of the PCCLs more clearly. **(Sections 4.3, 4.13, 7.4, 8.6: *Objective 3*).**

The Macmillan Support Programme:

- The Macmillan Support Programme was highly regarded by those who used it, primarily as a place to discuss successes/challenges with peers. **(Sections 6, 8.8: *Objective 8*).**
- The Macmillan Support Programme was essential, at least initially, since many PCCLs had no idea what was expected of them. . **(Sections 6, 8.8: *Objective 8*).**
- Although not perfect, many PCCLs would have floundered without the Macmillan Support Programme. **(Sections 6, 8.8: *Objective 8*).**
- Support for PCCLs new to the role was essential, but was needed less over time as PCCLs 'grew into their role'. It may still be needed in some format for incoming PCCLs. **(Sections 6, 8.8: *Objective 8*).**

The Future:

- Most PCCLs wanted the role to continue so that they can continue to develop strategy and improve cancer services in primary care. **(Sections 4.9, 4.16, 6.2: *Objective 10*).**
- It is still 'early days'. The next two years should show major improvements in primary care cancer as a result of PCCL input. **(Sections 7.4, 7.7: *Objective 10*).**
- In areas where recruitment has been difficult, innovative ways of providing PCCL services need to be tested to ensure that inequalities are not perpetuated. **(Section 6.2: *Objective 1*).**

- The new GMS contract could provide PCCLs with a route into practices in those areas where this has proved difficult. **(Sections 4.7, 4.16: *Objective 1*).**

Abbreviations

CE:	Chief Executive
CHD:	Coronary Heart Disease
CLS:	Collective Learning Set
COREC:	Central Office for Research Ethics Committees
CPS:	Central Programme Support
C&SW:	Central, South and West of England Macmillan Region
GMS:	General Medical Services
GP:	General Practitioner
GPwSI:	General Practitioner with a Special Interest
GSF:	Gold Standards Framework
LASER:	London, Anglia and South East England Macmillan Region
LREC:	Local Research Ethics Committee
MREC:	Multiple Research Ethics Committee
MSP:	Macmillan Support Programme
NHS:	National Health Service
NICE:	National Institute for Clinical Excellence
PCCL:	Primary Care Cancer Lead
PCG/T:	Primary Care Group/Trust
PCG:	Primary Care Group
PCO:	Primary Care Organisation
PCT:	Primary Care Trust
PDP:	Personal Development Plan
PEC:	Professional Executive Committee
PMS:	Personal Medical Services
R&D:	Research and Development
RM&G:	Research Management and Governance Organisation
SHA:	Strategic Health Authority
SPSS:	Statistical Package for Social Sciences

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1. Introduction

More than one in three people in England will develop cancer at some stage in their lives, and one in four will die of the disease. Every year, over 200,000 people are diagnosed, and around 120,000 people die from cancer. In the UK, cancer is amongst the three leading causes of death. The most common killers are lung, breast, colorectal and prostate cancer which account for 62,000 deaths each year. The Government recognised that something should be done in order to improve cancer survival rates.

1.1. The Calman Hine Report:

The Calman Hine Report, published in 1995, [1] highlighted the importance of primary care and cancer. It noted that: 'The primary care team is a central and continuing element in cancer care for both patients and their families from primary prevention, pre-symptomatic screening, initial diagnosis, through to care and follow up or, in some cases, death and bereavement.' It also stated that 'Primary care is seen as the focus of care.' However, it did not set out what to do or how to make this happen.

1.2. The NHS Plan:

In July 2000, the Government unveiled a blueprint for reforming and modernising health and social care in England in pursuit of its vision of a modern, patient-centred health service. There was a lack of national standards; out-dated demarcations between staff and barriers between services; a lack of clear incentives and levers to improve performance and over-centralisation and disempowered patients. The Government identified ten priorities for improving health and social care which included cancer care. [2]

1.3. The NHS Cancer Plan:

The NHS Cancer Plan, [3] published in September 2000, was the 'first ever comprehensive strategy to tackle cancer drawing together a programme of action linking prevention, diagnosis, treatment, care and research.' It also recognised the key role that primary care plays for people with cancer. It stated that: 'People with cancer spend much more of their time living in their own homes than in hospital or hospice. GPs, district nurses, social services, home nursing services and community specialist palliative care teams provide essential support for patients and their families at different times.' It also took the first steps to taking some action in this area. The Cancer Plan committed an investment of £3 million per year for three years, in partnership with Macmillan, to establishing the role of primary care cancer lead clinician (PCCL) in each PCT. It also gave a commitment to establish a primary care cancer dataset as a tool for clinical governance in primary care, and committed to investing £2 million per year for three years in training for district/community nurses in palliative care.

1.4. Primary Care Cancer Leads (PCCLs):

The introduction of PCCLs in each PCT, as set out in the NHS Cancer Plan, was aimed at involving primary care professionals in the Cancer Networks, and providing them with the opportunity to contribute to Network development. In addition, PCCLs would raise standards of care within their PCTs and improve communication and understanding across primary, secondary and tertiary care.

The Department of Health and Macmillan Cancer Relief jointly invested in the PCCL initiative. Macmillan contributed a total of £2.2 million over three years for the PCCL Support Programme.[4] The Department of Health funding (more than £6 million over 3 years) was to enable the PCCLs to have dedicated time to contribute to the development of Cancer Networks and raising the standard of cancer care within the PCG/T. There are five main aspects to their role:

- To provide strategic leadership within the PCG/T in line with the NHS Cancer Plan to develop services for cancer patients
- To contribute to Network development and, where appropriate, to represent the PCG/T and primary care in the Cancer Network
- To contribute to the development of network service delivery plans in order to streamline patient care
- To raise the standards of cancer care within the PCG/T in collaboration with the clinical governance lead
- To ensure that services are responsive to the needs of people affected by cancer. [4]

1.5. The Macmillan Support Programme (The MSP) for PCCLs:

Macmillan worked with three Cancer Networks and others with direct experience of the new role, to develop a programme which was:

- Focused - on the role set out in the job description,
- Structured – with specific tracks of activity for defined stages through the overall time period set for the programme (Autumn 2001 until Spring 2004),
- Flexible – able to respond to the different needs and preferred learning styles of individuals as they developed in the role.

During the design stage of the Support Programme Macmillan was very pleased to discover opportunities for close working arrangements between the MSP and related national development programmes, for example: the Cancer Network Development Programme, the roll out into primary care of the Cancer Services Collaborative, the Primary Care Collaborative Programme and the PCT Development Programme.

The MSP has responded to the following PCCL needs:

- Knowledge: clinical or organisational understanding of cancer and cancer services.
- Skills: the personal abilities that will enable them to be effective in the role.
- Access to information: data and information about cancer services that will enable them to make effective use of limited time.

The programme offered:

- Individual learning and support: for each PCCL shaped and maintained through a personal development plan.
- Collective learning and support: for natural local groups of PCCLs, 'Collective Learning Sets' aligned to the Cancer Networks, together with a series of 'regional' conferences.
- Central Programme Support: available to all PCCLs, including a telephone 'help line'; website based information; topic based materials and toolkits (MSP 'Working Briefs.'). [5]

1.6. The New GMS Contract:

The new GMS contract [6] was launched in 2003 and allows the work of a GP to be more strictly defined and costed. It will widen the range of services in primary care; enable PCTs and practices to design services to meet local needs; create new roles for nurses and other health professionals; improve the attractiveness of primary care as a career choice for doctors; improve the quality of services; allocate funding more fairly and enable a major overhaul of GP surgeries.[6] However, as yet little is known about cancer patients' use of primary care after diagnosis, so the quality of data held on this growing population of patients is important for future management.[7-9]

'The new GMS contract is a practice-based contract with investment for infrastructure and running costs upfront via a global sum, distributed fairly in line with the weighted needs of the patients to reflect GP and practice workload and complexity'.[6] It means rewards for family doctors based on the quality of care they provide for patients, rather than simply the numbers of patients they treat. Points achieved for reaching certain specified 'quality' targets can be converted to funds for the practice. A total of 1050 points are available but cancer has only 12 specific points, raising concerns that GPs will devote more effort to other diseases, for example diabetes, where more points are on offer. This could have consequences for the PCCLs.

2. Background

The Department of Health, in partnership with Macmillan Cancer Relief, was responsible for establishing the role of PCCL. They identified the need to evaluate the current position and evaluate the process of implementation, and inform future policy and practice. The evaluation was carried out during the final ten months of the programme, rather than at the end, so that messages were available to inform future funding decisions.

2.1. Aims and objectives:

The aim of the study was to evaluate whether or not the nomination of a lead clinician at PCT level for cancer (the Primary Care Cancer Lead Clinician or PCCL) in the primary care setting, with a defined role description, dedicated time and a personal support programme accelerates the achievement of national and local service improvement targets through demonstrable and measurable change processes.

The objectives were:

1. To examine the extent and nature of PCTs' use of PCCLs
2. To examine the level of national and local service improvements attributable to the PCCLs
3. To explore progress on the five strategic elements of the PCCL Job Description
4. To identify characteristics of PCCLs that have ensured their effectiveness, and how these change over time
5. To examine the impact of the PCCLs' clinical background on how they perform their role
6. To identify the factors associated with the successful achievement of the PCCL role
7. To examine the impact of relations with PCTs, Cancer Networks and local GPs on the PCCL role
8. To examine the impact of the Macmillan Support Programme on PCCL effectiveness and identification of any changes that might be required
9. To identify and quantify the costs of providing PCCL services

10. To identify how the PCCL role might develop in the future and to make recommendations.

Using measures of structure, process and (where available) outcome, the study was designed to evaluate the effectiveness, efficiency and costs of PCCL schemes and identify any possible future changes.

This study was conducted between 1 June 2003 and 31 March 2004 (10 months) and comprised four phases. Phase 1 was a national postal survey of PCCLs and Chief Executives (or their substitutes) in all PCTs in England. Phase 2 consisted of case study interviews with key informants in six sites in different Cancer Networks. Due to the short time scale available for the study, Phase 2 partly overlapped with Phase 1. Phase 3 also ran concurrently with Phase 2 and consisted of collecting the views of the Macmillan Support Providers. Phase 4 was a period for finalising data analysis, writing up the final report and making recommendations.

3. Methods

A mix of methods was used, including national postal surveys, case studies and interviews. The details of each phase of the study are set out below.

Phase 1: National Postal Surveys:

In order to identify the extent and nature of PCCL activities in PCTs nationally, a postal survey was conducted of all PCCLs and PCT Chief Executives (or their substitutes) in England. This phase provided an overview of the development of PCCL services across England.

Details of PCCLs and their place of work were provided by Macmillan Cancer Relief. Details of PCT Chief Executives were obtained from the internet. After piloting locally in 2 PCTs, questionnaires were sent to all PCCLs and Chief Executives in all PCTs in England, followed by one postal and one email reminder. Questions were mainly of the 'tick box' or 'Likert scale' type, with some opportunity for individual comments in open-ended questions. It was hoped that such an easy to complete questionnaire would help to ensure a good response rate. The questionnaires covered:-

- Priority given to various strategic objectives of the PCCL
- Time commitments for staff
- Staff turnover
- Progress with national and local targets
- Cancer-specific educational background and training (for PCCLs)
- Level of PCT infrastructure and support
- The costs of setting up and running the schemes
- Extent of collaboration with the non-statutory sector and local authorities
- Extent of interaction with Cancer Networks.

Some of the questions were common to both PCCLs and Chief Executives but others were specific to one group. The questionnaires can be seen in Appendices 1 and 2.

A covering letter describing the nature of the study was sent out with the questionnaire together with a pre-paid return envelope. A reminder was sent to non-responders after 2 weeks, together with another copy of the questionnaire. After a further 2 weeks, PCCLs and Chief Executives were contacted by email, and the Chief Executives were asked to remind the person who was dealing with the questionnaire that it should be returned. It had been anticipated that in some instances the Chief Executive would pass on the questionnaire for completion by an alternative senior manager with closer working links with the PCCL. Previous experience allowed us to anticipate achieving a 60-70% response rate. Questionnaires were coded and entered into SPSS (Version 11) and descriptive statistics were used. Thematic analysis of free text comments was also undertaken. This Phase provided information on the extent and nature of PCTs' use of PCCLs; the level of national and local service improvements associated with the PCCLs; progress on the five strategic elements of the job specification; the factors associated with success; the impact of relations with PCTs (for PCCLs), Cancer Networks and local GPs; the costs of providing the PCCL service; and how the PCCL role might develop in the future. (*Objectives 1,2,3,6,7,9,10.)*

Phase 2: Case Studies:

The aim of this phase was to develop a picture of the implementation and development of the PCCL scheme and its continuing progress and achievements across England.

Site selection: Six case study sites were selected purposively from the three Macmillan Provider Regions in England (LASER – London, Anglia and SE England; C&SW – Central and SW England; EM&N – East Midlands and Northern England) to ensure national coverage. There are 34 Cancer Networks across England and two were randomly selected per Macmillan Provider Region, stratified to include one mainly urban and one mainly non-urban (n=6). Each case study site therefore corresponded with a single Cancer Network. The number of PCTs in the chosen Cancer Networks ranged from 5 to 17. In each, up to 5 PCTs were invited to take part in the study (n=30). Sampling was stratified to ensure the inclusion of urban and rural areas and PCTs where the PCCL programme was well and less well developed. Advice on the latter was sought from the Macmillan Lead Providers in each Region. All PCTs in England provide or commission health services for their local communities – a role previously carried out by

98 health authorities. Each PCT has a PCCL, assuming one has been appointed. The sampling strategy was designed to maximise the number of PCCLs included in this phase, whilst at the same time setting their role within the context of the local area and providing comparisons between PCCLs.

Using this sampling procedure 30 PCTs were selected. Ideally we would have used the findings from the postal survey to inform the selection of the sample for Phase 2. However, due to the short time-scale for this study it was necessary to select the PCTs to study in depth before the analysis of the postal questionnaires was complete. Once the PCTs had been selected, advice on ethical approval was sought.

Telephone interviews with stakeholders: The following was the spread of interviews with key informants intended to be conducted in the six case study areas (total numbers of intended informants shown in brackets). Actual numbers of informants who took part are shown in Table 23.

- PCCLs (30)
- A sample of non-PCCL GPs (30)
- PCT Chief Executive, or substitute (30)
- Oncology Consultants (12)
- Cancer Network Director (6)
- Hospital Trust Cancer Services Manager (6)
- GPwSIs specialising in cancer/palliative care (6)
- Patient Representative sitting on the Cancer Network Services Strategy Group for primary care (6).

The interview topics included:-

- How PCCLs were identified and recruited
- Views on the Job Description and clarity of task boundaries
- Source of funding and method of payment
- Use of protocols and quality standards

- Achievements
- Changes over time
- Local targets
- Links with Cancer Networks
- Training and accreditation
- Capacity planning.

PCCLs were asked specifically about job satisfaction and workload. Respondents were also asked about their perceptions of the value and shortcomings of their role.

In order to include some face-to-face contact with PCCLs, one team member (BL) attended the National Development Programme meeting held at Heathrow in October 2003. At the same meeting, discussion with patients/users present at the meeting was also possible.

Data Analysis: The telephone interviews were semi-structured. All the interviews were taped, with the respondents' permission, and analysed using the framework approach [10,11]. This involves identification of key themes and interpreting the findings in the context of existing policy. The aim was to build up as complete a picture of PCCL schemes as possible. This aspect of the study provided further information on the extent and nature of PCTs' use of PCCLs; the level of national and local service improvements associated with PCCLs; the characteristics of PCCLs that ensure their effectiveness and how these change over time; the impact of the PCCLs, clinical background on how they perform their role; the factors associated with success; the impact of relations with PCTs (for the PCCLs), Cancer Networks and local GPs; how the PCCL role might develop in the future *(Objectives 1,2,4,5,6,7,10)*.

Analysis of Costs: Information to provide an estimate of the costs of setting up and running the PCCL scheme were collected from the postal questionnaires. Previous experience by some of the applicants in collecting such data suggested that it would available in a number of different formats making comparisons across PCTs problematic. Attempts were made to collect as much information as possible including the employment costs of the PCCLs and associated staff, overheads and any additional costs incurred by the PCT in the setting up and running of the scheme. These included time allocations for the PCCL, office space, support costs (administration, secretarial, computing etc)*(Objective 9).*

Phase 3: Macmillan Support Programme Providers:

This phase was conducted concurrently with Phase 2. Face-to-face interviews were conducted with the three Macmillan Support Programme Providers. The interviews explored the support providers' relationship with PCCLs and their views on their impact and future direction. (*Objectives 7,8.).*

Phase 4: Writing up and Dissemination:

The final 2 months of the study (February and March 2004) were concerned with data analysis, writing the Draft Final Report and making preparations for dissemination.

4. Postal Survey Results

Postal questionnaires were sent in October 2003 to all PCCLs identified in England from a list provided by Macmillan, followed by one postal and one email reminder. Similarly, postal questionnaires were sent to the Chief Executives of all PCTs. The accompanying letter to the Chief Executives suggested that if they felt it to be appropriate, the questionnaire could be passed on to another senior manager working more closely with the PCCL. Not all PCTs had a PCCL in post at the time of the survey, but those without a PCCL were asked to complete as much of the questionnaire as they were able.

After discussion with COREC, it was agreed that research ethics approval was not required since the study constituted an evaluation of an intervention. The postal survey was considerably delayed by the newly introduced national research governance procedures [12] which necessitated individually contacting all 59 RM&Gs, as well as those PCTs acting alone.

The Primary Care Cancer Lead Clinicians (PCCLs)

4.1. Response rates:

A total of 269 questionnaires were sent out to the PCCLs on a list provided by Macmillan and 192 were returned, a response rate of 71%. Five of these were returned uncompleted as the recipients were not PCCLs so that 187 were entered into SPSS and used in the analysis. Not all of the respondents completed all sections of the questionnaire so total numbers may differ in the tables set out in this Report.

4.2. Characteristics of the PCCLs:

A total of 128 (69%) PCCLs were GPs, 48 (26%) were Nurses and 9 (5%) had another background. Of the latter, three were Pharmacists, two were Public Health Consultants and there was one each of a Dentist, Palliative Medicine Consultant, Medical Services Lead at a Hospice, Clinical Governance Manager and a Macmillan Team Leader. 118 (66%) had a special interest in cancer over and above their daily clinical role before taking up their PCCL post.

Of the respondents, 99 (53%) were male and 87 (47%) were female. They ranged in age from 34 to 63 years, with a mean of 48 years. The mean age of the male PCCLs was 48 years (range: 34 to 61 years) and for females it was 47 years (range: 35 to 63 years).

52 (27%) of the responding PCCLs did not work in a practice, but of those who did, 63 (34%) were in a GMS practice and 71 (39%) were in a PMS practice.

172 (94%) PCCLs worked in a single PCT; seven worked across two PCTs, three worked in three PCTs and one PCCL worked across five PCTs.

4.3. Development of the PCCL role:

Key achievements: A number of key achievements were identified by the PCCLs (Table 1), foremost of which concerned raising awareness of primary care cancer issues and developing relationships with key individuals locally. It is unsurprising that such issues were regarded as key achievements since PCCLs were following the patterns identified elsewhere (e.g. setting up Total Purchasing Pilots, PCGs and PCTs) where the first few years of any new initiative are concerned with precisely these factors of developing relationships, getting the infrastructure sorted, and deciding what needs to be done and where the obstacles are. [13] In addition, the PCCL scheme was initiated at a time when many PCGs were reorganising into PCTs, making the task of the PCCLs even more problematic. It was necessary for the PCCLs to develop links within their own PCTs, with local practices, with secondary care providers and with the Cancer Network. This was made more difficult by the limited time PCCLs were able to devote to the task, recognised by almost everyone taking part in this study, and also by these organisations sometimes being unaware of the existence of PCCLs and unsure of their role. Emphasis was placed on achieving a recognisable primary care presence on the Network and also on the PCT, either by being a PEC member (the most favoured option), or by being invited to the PEC for specific items or to give a presentation to the PEC. Establishing such links was regarded as being an essential prerequisite to moving on to influence commissioning, improving service provision and raising the profile of cancer in primary care settings. Many of the PCCLs felt that they had had at least some success in this.

Table 1: Key achievements identified by PCCLs

Communication, promotion, relationships
Awareness raising
Setting up of, membership of and chairing cancer specific groups
Baseline Assessment
Gold Standards Framework and palliative care
Out of hours services
Two week wait monitoring
Local service developments

Coupled with developing relationships and improving communication were efforts to raise the awareness of cancer at PEC and PCT Board level, and raising awareness of primary care issues with regard to cancer at Network level. Raising the profile of cancer at PCT level was considered to be essential to ensure cancer services were commissioned and that funding was made available, and for the role of the PCCL to be continued in the future. Raising the profile of primary care cancer services at the Acute Trust was regarded as exceptionally important but sometimes difficult. Much of the successful liaison and awareness raising depended on the receptiveness of individuals and on the characteristics of the PCCLs themselves. One way by which PCCLs could raise awareness of primary care cancer was by becoming chairs or members of local cancer groups or by setting up such groups where none existed previously. Many such groups have been set up by PCCLs, known by a variety of names (cancer group, cancer services sub-group, cancer steering group, cancer implementation group etc). Some groups were for PCT members only but others included members from the Cancer Network and secondary care, and sometimes patients or users.

There were two major practical issues identified by the PCCLs as key achievements: the Baseline Assessment exercise and implementing the Gold Standards Framework (GSF) for palliative care. PCCLs were either implementing baseline assessment or rolling it out across the PCT. The process involved collecting data from practices about their populations and cancer diagnoses. The GSF is designed to promote community palliative care and

> *'to enhance the care of patients in the community with a life threatening illness by supporting the further development of palliative care skills of district nurses through education and the use of pathways.'*

Much of the work around GSF involved raising interest amongst GPs, nurses and consultants, setting up groups, linking with hospices, pathway development, ensuring staff were in place, and monitoring progress. Coupled with GSF developments were plans to set out of hours palliative care in place with appropriate proformas or protocols.

Other key achievements identified by PCCLs were associated with the two-week wait guidance, educating practices, developing referral proformas and liaising with practices and the Acute sector.

As well as these activities which are generic in nature, there were other local service based initiatives highlighted by PCCLs as key achievements. Some examples of these included: developing cancer resource packs for practices, implementing hospice at home, care of the dying schemes, mapping the cancer journey and shaping care pathways, improving screening, monitoring the patient/carer experience, setting up education programmes, auditing referrals and appointing staff to key posts.

Factors which have contributed to the achievements: Prior knowledge of the local health economy was regarded as being very important in contributing to the achievements identified above. This is perhaps linked to the inevitable time lag in setting up new initiatives where developing relationships and identifying key contacts usually take up much of the initial time period. Being part way there means that initiatives can be started sooner and changes put in place earlier. As one PCCL put it

> *'previous experience means a flying start.'*

Furthermore, some PCCLs identified being known locally in a long standing capacity as a GP, perhaps with a known interest in cancer, as giving them local credibility so that they were more readily accepted in their new role. Some quotes are set out below:

'recognised as a local champion'
'acceptance of local GPs'
'track record and local credibiltiy'
'need political nous.'

Coupled with local knowledge and being known locally was the support PCCLs had received from a number of sources, all of which had assisted in their achievements. Three organisations in particular were regarded as very important in terms of the support they provided: the PCT, the Cancer Network and the Macmillan Support Programme. PCT management and administrative support was identified as being particularly significant in allowing the PCCLs to develop their role. In conjunction with this, it was also helpful where PCT staff were aware of the PCCL role so that it did not have to be 'sold'. Existing local knowledge and PCT support gave the PCCL a head start in getting initiatives off the ground. Similarly, support from the local Cancer Network was also identified as important. The Macmillan Support Programme was well regarded, particularly in providing knowledge and information, but primarily in back up, support and somewhere to discuss problems and learn from others and to feel less isolated.

Another factor PCCLs considered had contributed to their achievements, and linked to those already identified above, were the relationships that existed between themselves and other key individuals at all levels in the local health economy. In some cases these already existed, in others PCCLs had worked hard to develop such links.

It is clear, not only from the postal survey, but also from the case studies, that being a PEC member was seen as particularly useful as a means of getting the PCCL voice heard. As one respondent put it

'being a GP and PEC member gives clout.'

However, the issue of PEC membership ties in with other forms of influence and support. The whole issue is explored in more detail in the commentary on the case study interviews.

Two final factors, time and personal skills, were also regarded as contributing to achievements. In particular, dedicated, funded time meant that there was time available to contribute to the requirements of the post, but, as will be seen later, this was also frequently regarded as insufficient to complete all that was expected of the role. PCCLs rightly viewed their commitment, stubbornness and personal application to the role as important in helping them to achieve the objectives of the post.

Things that worked less well: Inevitably, some aspects of the PCCLs' role had worked less well and the most notable of these was engaging others, especially GPs. Difficulties had arisen for some PCCLs when they had tried to complete the Baseline Assessment but had received a poor response from practices. Difficulties were also encountered in persuading GPs to become involved if cancer was not regarded as being high on their agenda. One PCCL commented:

'raising the profile of cancer in practices – it's either high or not there!'

Some PCCLs had encountered problems in engaging their PCT management to take an interest in their role and, again, being a PEC member was seen as an advantage in raising their own profile. In some instances the Cancer Network and the Acute sector were also proving difficult to engage with primary care perspectives on cancer care and questions of competing priorities. Coupled with this lack of engagement was a lack of support, manifested either as a general lack of interest in the role, or a lack of specific practical administrative support.

Lack of communication with the PCT, Cancer Network and secondary care were areas that had worked less well than expected for many PCCLs. Again, since one of the main achievements identified by the PCCLs was in building relationships with key individuals and organisations, the lack of engagement, support and communication meant that progress had been less than anticipated. Aside from these general difficulties, some PCCLs mentioned that commissioning, Baseline Assessment and palliative care in particular had worked less well than expected. With regard to commissioning, some PCCLs had failed to have any impact on influencing the PCT in commissioning cancer services.

Lack of engagement with GPs had meant that the Baseline Assessment questionnaire to practices had been '*poorly received*' or '*a disaster.*' For a few PCCLs the GSF for palliative care had been difficult to implement, particularly out of hours aspects. Finally, some PCCLs commented that financial constraints within the PCT had meant that resources were limited for cancer services and less had been achieved than had been anticipated.

The main barriers to achievement encountered: Unsurprisingly, barriers to achievement mirrored the factors that had worked less well. Foremost of these were attitudes, commitment and relationships. These were apparent at all levels, from GPs to practices to Networks, to secondary care and consultants. Persuading reluctant key individuals to take primary care cancer seriously could sometimes be an uphill struggle for some PCCLs. This was due to lack of time, respect from managers and a suspicion of the PCCL role. In some instances there was a reluctance or a resistance to change which made it difficult for PCCLs to promote the cause of primary care cancer. It was noted that the PCT agenda is large and cancer services are a very small part of this, making engagement sometimes problematic. Coupled with these attitudes was a lack of support at all levels. A majority of PCCLs had little in the way of administrative, secretarial or managerial support. Feelings of being 'dumped on' were widespread with the cancer agenda seen as too large for one session a week which was all most PCCLs had to devote to the role. Lack of knowledge or information to assist in carrying out their role was also a problem for a smaller number of PCCLs.

Lack of funded time to perform all that was expected of them was a continuing problem. This was linked to a lack of funding with some PCTs having their own financial difficulties. Finance and time are linked and both were in short supply for most PCCLs. Lack of time meant that they felt constantly under pressure to complete all that was required in the time available. Some organisational barriers were also mentioned by some PCCLs. These included unclear management structures, a lack of clear objectives, difficulties in relating to the PCT/PEC, ongoing changes, lack of motivation, the extent of the remit and a lack of momentum to drive change. Being a lone voice for cancer could be an isolating experience.

Priorities for the future: In many cases, priorities for the future simply meant continuing with what had already been started – developing and improving relationships, promoting primary care cancer services, palliative care and GSF, referrals, pathway development, Baseline Assessment and setting up datasets, and screening/preventive services.

Improving and developing relationships, particularly between primary and secondary care and with GPs in local practices were most likely to be mentioned by PCCLs. To a lesser extent, developing relationships with the PCT and Cancer Network were also cited as priorities. It is possible that many PCCLs were either working with a supportive PCT, or had already during their two years or so in post, improved relationships and had moved on to focus attention more directly with the interface between secondary and primary care and GPs. Awareness raising of the significance of primary care was an ongoing priority with attempts to redress the secondary care bias in cancer services being of particular importance.

Unsurprisingly, setting up, developing and rolling out the GSF for palliative care was a priority for many PCCLs, particularly in the context of establishing out of hours services or developing specialist palliative care. Organisational developments in the context of referrals, proformas and two week wait monitoring were mentioned by a number of PCCLs. Data collection and Baseline Assessments were also ongoing priorities, as were the development of patient pathways of care. Some PCCLs also mentioned the setting up and further improvement of screening in primary care. A small number of PCCLs planned to improve patient/carer participation.

Some PCCLs noted that they had or were going to resign, and others indicated that they could see no future in the role. This negativity was frequently associated with uncertainty as to whether funding for the post would be continued by the PCT from April 2004. Others, however, indicated that their priority was to ensure that funding did continue. Such outrightly negative comments were, however, very much in the minority, and most

PCCLs were hoping that the posts would continue if the remit could be made more manageable.

Committee membership and meeting attendance: Table 2 sets out the committees that PCCLs were members of and the meetings that they attended. The results show that attendance at the various meetings of significance in the PCT was comparatively rare. PCCLs were most likely to attend the Cancer Network meetings, in line with one of the requirements of their job description. Of the 42 Nurses who responded, 12 (41%) were PEC members compared with 36 (29%) of the 124 GPs: the differences were not significant. Examples of 'other' meetings in Table 2 included; cancer local implementation groups, cancer steering groups, cancer forums, cancer strategy groups, commissioning groups and palliative care groups.

Table 2: Committee membership and meeting attendance of PCCLs

Type	Do attend		Do not attend	
	No.	%	No.	%
PEC membership	53	30.5	121	69.5
PCT Board membership	22	12.8	150	87.2
Cancer Network Executive Team	33	20.0	132	80.0
Attend PEC meetings	82	48.2	88	51.8
Attend PCT Board meetings	42	25.9	120	74.0
Attend Cancer Network meetings	157	90.2	17	9.8
'Other' PCT meetings	126	89.4	15	10.6

Support from the PCT: PCCLs were asked to indicate whether they felt supported by their PCT on a scale from 1 to 5 where 1 was 'not at all' and 5 was 'a great deal'. The results showed that 51 (28.6%) gave a score of 1 or 2; 46 (25.8%) gave a score of 3; and 81 (45.5%) gave a score of 4 or 5, indicating a high level of support from PCTs. However, 10 (5.6%) gave a score of 1 and over a quarter gave a score of 1 or 2, indicating some dissatisfaction from a sizeable minority of PCCLs. There were no differences between doctors and nurses in the level of support they felt they received from the PCT.

4.4. Progress with National and Local Targets:

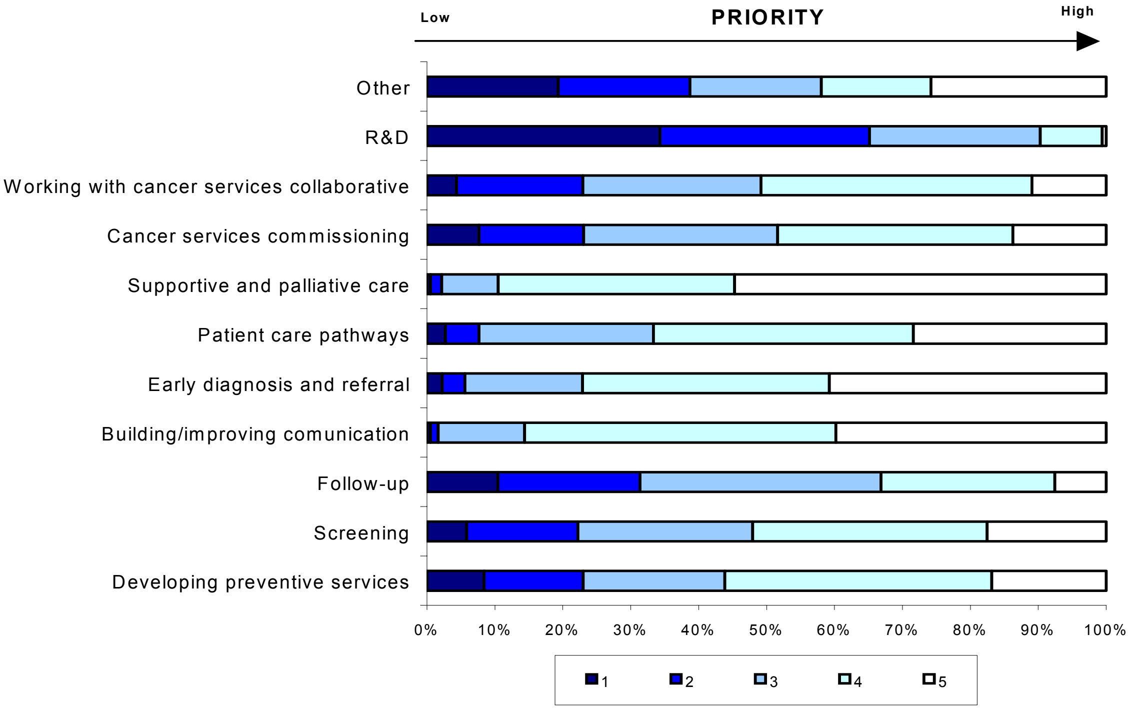
Awareness of targets: A total of 172 (95%) PCCLs knew what their local cancer targets were, and 176 (97.8%) were aware of the national cancer targets. The information that

PCCLs thought that they should receive was primarily associated with local progress against national targets, provided on a regular basis – quarterly or annually, so that shortcomings could be identified. Some stated that they already received all of the information that they required, although they were in a minority.

Issues in cancer care being focused on by PCCLs: PCCLs were asked to indicate, on a scale from 1 to 5 (where 1 = low priority and 5 = high priority) the cancer care issues that they were focusing on. Figure 1 shows that the major areas of focus were supportive and palliative care (long pale bar), followed by building and improving communication and early diagnosis and referral. Research and Development (R&D) was the lowest priority (long dark bar).

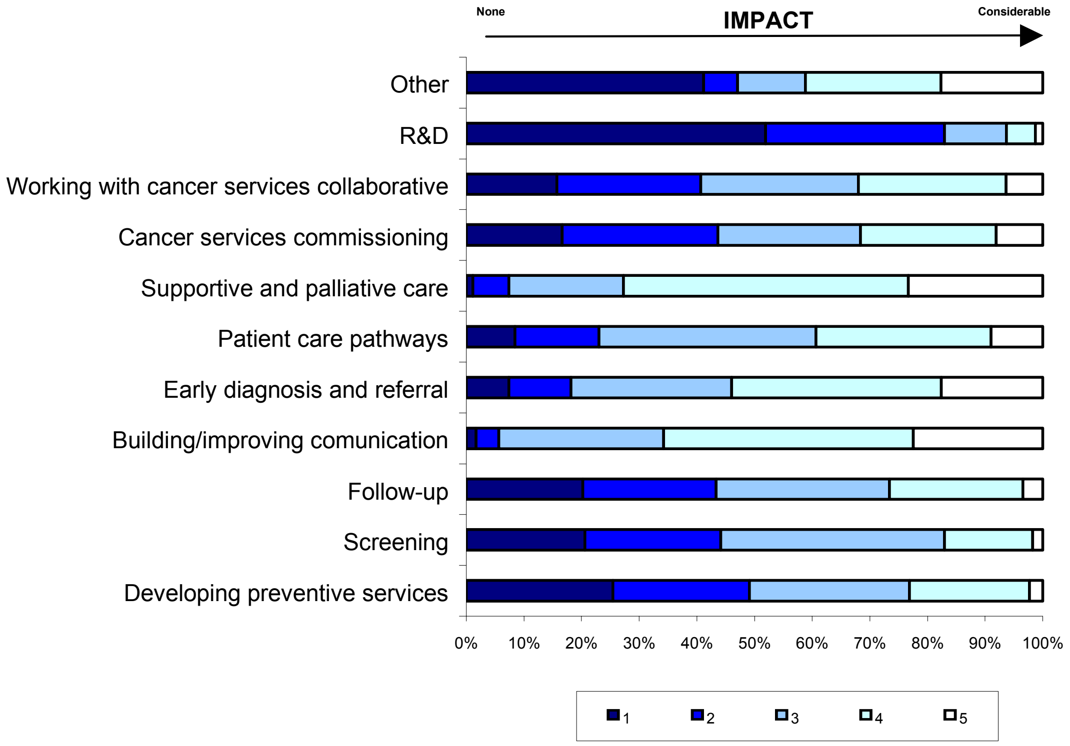
There were 14 responses identifying a specific focus under 'other'. These were GSF (3), education (3) and one mention each of cancer genetics, child bereavement, lymphoedema services, patient participation group development, out of hours provision, information leaflets, standards, improved data, and liaison with the Diabetes Forum.

Figure 1: Issues in cancer care being focused on by PCCLs



Impact of PCCLs on cancer care: PCCLs were asked to rate from 1 to 5 (none to considerable), the impact they felt they had on various aspects of cancer care. The results are set out in Figure 2. They were of the view that they had had the greatest amount of impact on supportive and palliative care, building and improving communication and early diagnosis and referral. These were the areas that they were specifically focusing on. Four 'other' areas of impact were noted: data collection; GSFs (2); strategy, planning and service development.

Figure 2: PCCL impact on aspects of cancer care



Development and quality of Baseline Assessment: One important aspect of the PCCLs' role was to complete the Baseline Assessment in each practice in their PCT, compiling cancer statistics to assist in service development. Table 3 shows that about one third of PCCLs gave a score of 4 or 5 for the extent to which the Baseline Assessment had developed but only one quarter thought that the quality of the data merited a score of 4 or 5. A sizeable minority of respondents thought that the quality of the data was at the poor end of the spectrum (scores of 1 or 2).

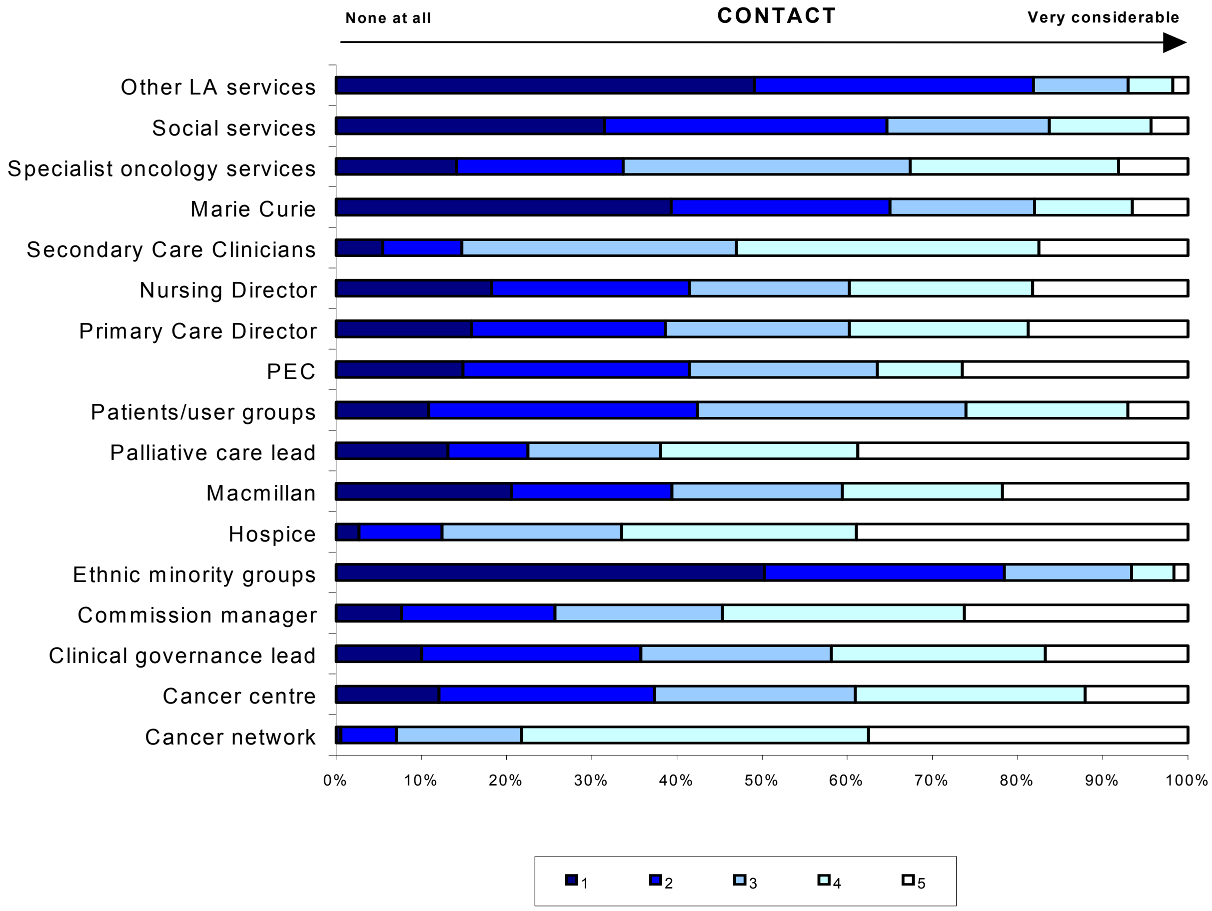
Table 3: Views of PCCLs on the development and quality of Baseline Assessment data

Score	1 (poor)	2	3	4	5(excellent)
Developed?	18 (10.1%)	35 (19.6%)	62 (34.6%)	46 (25.7%)	18 (10.1%)
Quality?	15 (8.8%)	50 (29.4%)	64 (37.6%)	32 (18.8%)	9 (5.3%)

4.5. Extent of Collaboration:

Contact with key individuals: PCCLs were asked to rate from 1 to 5 (none – very considerable), how much contact they had had with various groups and individuals. The results are set out in Figure 3. Contact had been highest with the Cancer Network, hospice, palliative care lead and secondary care clinicians (pale bars in the figure) and least with local authority services, ethnic minority groups and Marie Curie (dark bars in Figure 3).

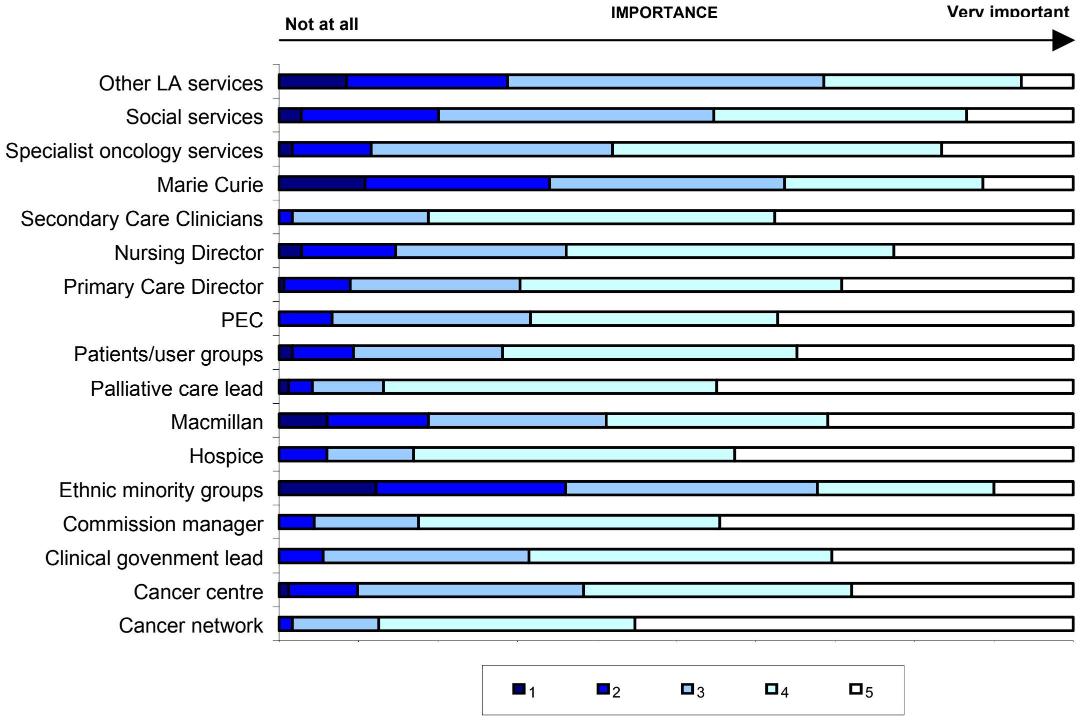
Figure 3: Contact with key individuals



Importance of working with key individuals and groups: The PCCLs were asked to rate from 1 to 5 (not at all – very important) how important they felt it was to work with various groups and individuals. The results are show in Figure 4. The most important groups were identified as the Cancer Network, secondary care clinicians, palliative care leads, hospice staff and commissioning managers (pale bars in the figure). Least important were minority ethnic groups, Marie Curie, social services, local authorities and Macmillan (dark bars in figure).

Contribution of PCCLs to raising the standard of care: Most respondents who thought that they, as PCCLs, had contributed to raising the standard of cancer care locally attributed this mainly to having raised the profile of primary care cancer at all levels. This was followed by contributions to palliative care services via the GSF, to shorter waiting times by means of the two week wait guidelines and by improving communication at all levels, and facilitating improved patient services.

Figure 4: Important groups and individuals for PCCLs to work with



Patient awareness of PCCLs: Only 20 (10.8%) PCCLs thought that patients would be aware of PCCLs and a further 17 (9.2%) did not know. Most PCCLs thought that patients would be unaware of the PCCL role for a number of reasons, including the fact that it is a strategic role so there is no need for patients to know since they would see the effects at second hand in terms of improved services. Another reason why patients would be unaware of PCCLs is the lack of publicity attached to the role. This again is a reflection of the strategic, behind the scenes nature of the work. A small number of PCCLs had been in contact with patients as part of their role and others had attended user groups or meetings or had met user representatives. Generally though, patient knowledge about PCCLs other than by some of those attending user groups, was thought to be non-existent. These findings were confirmed by a subgroup of patients and carers from the Network Development Programme (NDP) Partnership Forum who met with a study team member (BL) at the Heathrow NDP in October 2003.

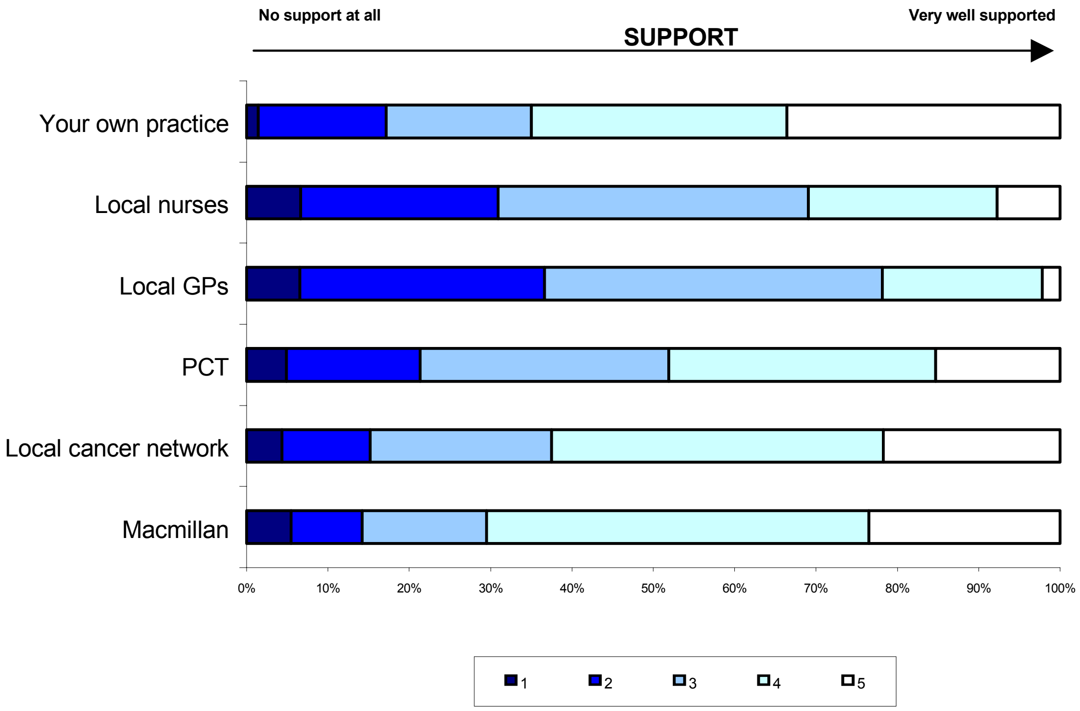
Advisory role of PCCLs: A total of 150 (82.4%) PCCLs advised on forward planning to the PCT, 146 (80.7%) advised on cancer care pathways, 136 (74.3%) advised on commissioning and 90 (49.5%) advised on audit.

Research Activities: Research was low on the PCCLs' agenda. Only 37 (20.1%) PCCLs said that they had taken part in cancer related research activities within their PCT. It was, however, encouraging that 28 PCCLs identified studies which could be regarded as research projects rather than audit or wishful thinking. These were wide ranging and included screening, referrals, out of hours services, patient information, support and psychological needs, choice of place of dying, genetics, smoking cessation and learning needs.

4.6. Extent of support:

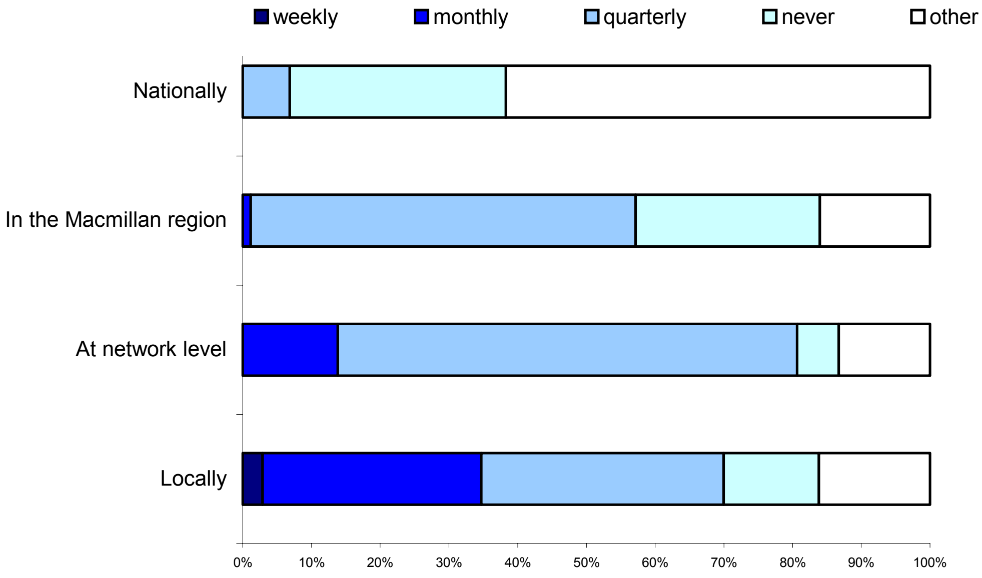
Extent of support: PCCLs were asked to rate how supported they felt in their PCCL work on a scale from 1 to 5 (where 1 = no support at all and 5 = very well supported). Most support came from their own practices (if GPs) and from Macmillan. Least support came from local GPs and Nurses and the PCT (Figure 5).

Figure 5: Extent of support to PCCLs



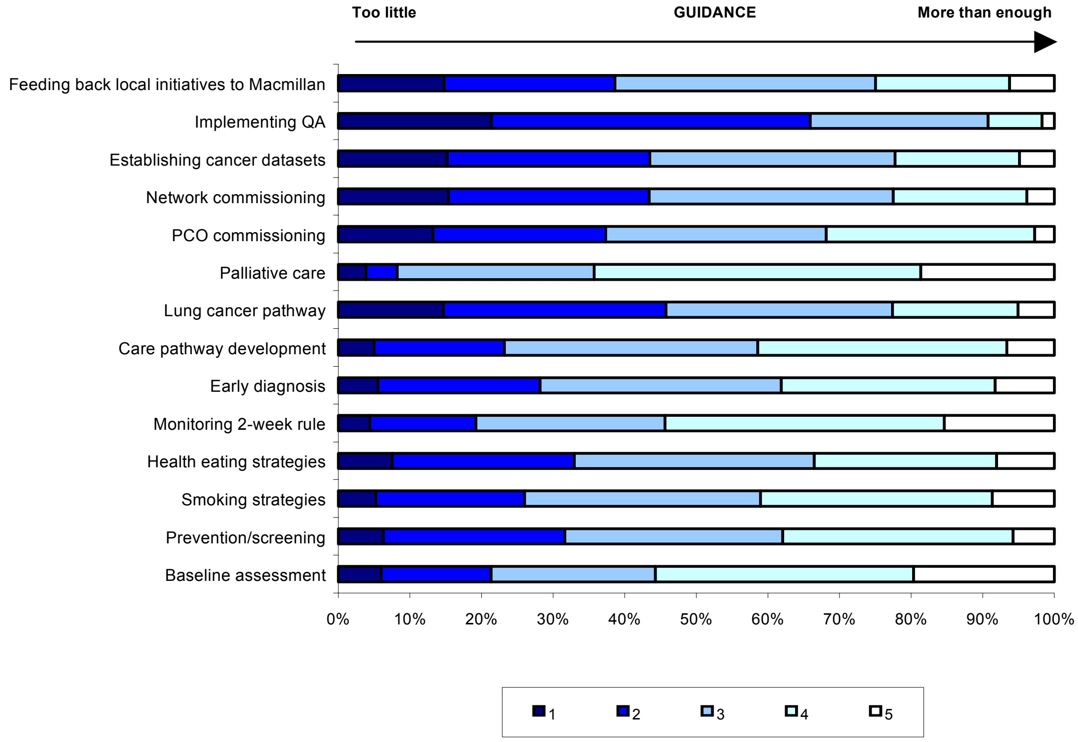
Frequency of meetings with other PCCLs: Figure 6 sets out the frequency of meetings held nationally, locally, in the Macmillan Region and at Network level where PCCLs could meet other PCCLs. Meetings were held most frequently locally and at Network level.

Figure 6: Frequency of meetings with other PCCLs



Guidance received by PCCLs: PCCLs were asked to rate from 1 to 5 (too little to more than enough) whether they felt they had received sufficient guidance to fulfil various aspects of their role. The results are shown in Figure 7. PCCLs received sufficient guidance on palliative care, two week waits and Baseline Assessment, but much less on feeding back local initiatives to Macmillan, implementing quality assurance, establishing cancer datasets, commissioning at Network level and lung cancer pathways. These results suggest options for the future.

Figure 7: Guidance received by PCCLs



4.7. Views of the PCCL role:

The PCCL Job Description: A total of 163 (87.6%) had seen the PCCL Job Description (see Appendix 3). They were asked to provide one word for the Job Description and the results are shown in Table 4. These have been divided into four groups: positive (approximately one third of responses); size related (one quarter); negative (about one third) and 'other' (around one tenth). Some of the size-related descriptions might also be regarded as negative (for example 'too much', 'extensive') so that negative comments slightly exceeded positive ones. However, the overall conclusion was that descriptions varied hugely.

Important personal attributes for PCCLs: Table 5 sets out the three most important attributes identified by PCCLs as necessary for their role. Most important were communication skills, enthusiasm, knowledge (local and about cancer) and perseverance/persistence. In addition to those listed in Table 5, the following were also provided:

'to have read Kafka'

'ability to suspend belief in reality'

'loud voice!'

'need to be visible in obscure places'

The attributes in Table 5 should be compared with those provided by the senior PCT managers (Table 15).

Table 4: One word for the Job Description

Positive descriptions	**Size descriptions**
Adequate – 7 Appropriate, Comprehensive – 3 Fine – 10 Good – 9 Satisfactory – 8 Supportive, Average, Basic – 1 each	Large – 21 Broad – 6 Long – 2 Too much – 2 Extensive -5 Excessive, short – 1 each
Negative descriptions	**Other descriptions**
Ambitious – 8 Challenging, Ambiguous – 2 Too general - 3 Daunting – 6 Impossible – 7 Unrealistic – 5 Optimistic, over ambitious, overwhelming, unachievable – 2 each Frightening, untenable, idealistic,	Vague - 4 Encompassing – 3 Agreed, useless, complex, fussy, generic, inadequate, inclusive, irrelevant, non-existent, strategic, subjective, unhelpful – 1 each

impractical, overblown, demanding, unbelievable, undoable – 1 each	

Ways in which the PCCL role has contributed to improved patient experiences: At such an early stage it proved difficult for PCCLs to identify whether or not their role had contributed to improved patient experiences since they were only a small part of the many cancer services initiatives. As a consequence a number (36) were uncertain or felt it was difficult to identify any such improvement. Others, however, were able to be more specific with some pointing to improvements in palliative care services (40) and others identifying improved access and speed of referrals, including two week wait changes (40). General improvements were also noted by an additional 36 respondents.

Table 5: Important Personal Attributes for PCCLs

Attribute	Number of times suggested
Communication skills	54
Enthusiasm	43
Knowledge	35
Perseverance/persistence	25
Vision, good relationships with colleagues, interest	20
Commitment	19
Negotiating skills, time	18
Determination, patience	17
Intelligence/ability	13
Motivation	11
Confidence, assertiveness, stamina/resilience, flexibility, organised	9
Teamworker, networking ability, tenacity	8
Hardworking, interpersonal skills	7
Sense of humour, leadership abilities	6
Dedication	5
Credibility, amenable, self-disciplined, influencing ability, experience, collaborative	4
Diplomacy, commissioning skills, persuasiveness	3
Extrovert, resourcefulness, having common sense, realistic conviction, durability	2

Personable, accessible, adaptable, ability to focus, approachable, conviction, belligerence, caring, stoicism, having contacts, self-motivated	1

Change over time in the PCCL role: A total of 112 (62%) PCCLs indicated that the role had expanded over time in a number of ways: in an unspecified manner (15), with greater PCT (9) and Network (9) involvement, and with more involvement in commissioning (9). Nine respondents indicated that they were more locally involved and oriented and six said that the role had become more strategic; but five stated it was more time consuming.

Impact of the new GMS contract : More than half of the comments on the impact of the new GMS contract on the PCCL role were concerned with the small number of quality points (12 out of a total of 1050) allocated to cancer. The view was that GPs' efforts would be diverted elsewhere where more points were to be gained. This would translate into even greater problems in engaging GPs and would do little to stimulate interest in primary care cancer and the continuation of the PCCL function. Other concerns were expressed that time would be reduced for PCCLs and practices would be more reluctant to release them. Some expected workload to increase as a result of the GMS contract.[6]

Conversely, approximately a quarter of respondents were of the opinion that the GMS contract would result in greater priority being given to cancer services. The main reason for this was that practices would be able to use the quality targets to improve care and this would, in turn, strengthen the PCCL role. As one person commented:

> *'GPs will be more interested, slightly'*

A few PCCLs were of the view that the PCCL role could be strengthened as practices would need their expertise to assist in further development of cancer registers to achieve their quality points. This would then assist PCCLs in getting more involved with practices for other aspects of their work.

A further quarter of PCCLs either indicated that they did not know what the impact of the GMS contract would be, or they thought that there would be little or no effect.

Views on decision to take up a PCCL post: PCCLs were asked to indicate, with hindsight, their feelings on their decision to take up their PCCL post, on a scale of 1 to 5 (where 1 = very negative to 5 = very positive). The results are shown in Table 6. Only a small number of PCCLs were very negative about having taken up their post, with the majority being positive.

Table 6: Views on the decision to become a PCCL

Score	Number giving score	% giving score
1 (very negative)	5	2.8
2	15	8.3
3	31	17.1
4	62	34.3
5 (very positive)	68	37.6

4.8. Impact of PCCLs:

Activities : Table 7 sets out the mean time spent on various activities during the week before the questionnaire was completed. A total of 164 PCCLs provided information on their activities and the time taken to complete them. The information has been divided into categories and the time taken converted to minutes to provide the mean amount of time spent on each activity. The mean total time was 7.44 hours (446 minutes) per week per PCCL. Just over half of the activity recorded was concerned with attending meetings on all aspects of their work. Preparation time for meetings added a further 45 minutes. The 'other' activities in Table 7 included planning, training, compiling a job description, reflecting, and being shadowed by a student.

Impact on PCCL's own GP practice: Not all PCCLs are GPs and the question about whether there had been any impact on the PCCL's own practice was relevant only to those PCCLs who were GPs. The results are set out in Table 8. A total of 65% of PCCLs were consulted about their activities by other GPs, 80% were used as a resource by their practice and 64% agreed that palliative care provision had changed since they took up their post. On a less positive note, 56% had difficulty in getting locum cover and 85% had increased workload on the days they were in the practice. However, there was little sign of resentment from other GPs in the practice.

Table 7: PCCL activities in the last working week

Activity	Total no. hours	Total no. minutes	% time	Minutes/PCCL
Meetings	612	36720	50.2	224.0
Conferences	125	7500	10.2	45.7
Preparation	122	7320	10.0	44.6
Reports/audit	59	3540	4.8	21.6
Reading	53	3180	4.2	19.4
Administration	51	3060	4.2	18.7
Projects/initiatives	48	2880	3.9	17.6
Emails	45	2700	3.7	16.5
Visits	31	1860	2.5	11.3
Letters	17	1020	1.4	6.2
Phone calls	10	600	0.82	3.7
Presentations	9	540	0.74	3.3
Other	38	2280	3.1	13.9
Total	1220	73200	100.0	446.3

Table 8: Impact of being a PCCL on the GP practice

Impact	Yes		No	
	No.	%	No.	%
Consulted by other GPs about PCCL activities	88	65	47	35
Resentment from other GPs	23	18	104	82
Used as a resource by the practice	108	80	27	20
Changed referral patterns	70	53	63	47
Difficulty in getting locum cover	70	56	56	44
Increased workload on days when in the practice	111	85	20	15
Changed palliative care provision	82	64	47	36
Other	12	67	6	33

4.9. The Future of the PCCL role:

Should the role continue? In view of the changed funding arrangements for PCCLs from April 2004, PCCLs were asked if they thought the post of PCCL should continue beyond 2004. A total of 90% (166) of the PCCLs felt that the post of PCCL should continue, 3% (6) thought that it should not and 7% (12) didn't know. Of those who had an opinion about the number of sessions that would be ideal, 122 (71%) said there should be more sessions, and 49 (29%) said there should be the same number as now.

Funding decision: According to the PCCLs, a total of 41 (22%) PCTs had made a decision to carry on funding the PCCL post after March 2004 and 58 (32%) had not. 85 (46%) PCCLs did not know whether a decision had been made. Of those PCTs that had made a decision, 36 (81%) had decided to fund at the current rate, 4 (9%) were to increase funding and 4 (9%) were withdrawing funding.

Improving the effectiveness of the PCCL role: PCCLs identified four main areas which might improve the effectiveness of the PCCL role, the most important of which was associated with improved PCT support and integration, ensuring PCT staff were aware of the role so that PCCLs could start their strategic role immediately rather than spending so much time on building relationships. A total of 43 responses were associated with this aspect and a further 8 commented on the importance of access to the PEC. Many PCCLs also identified additional support (secretarial, administrative and managerial) as being important in helping them to be more effective (23). More time for the post was another factor for 24 respondents and funding issues were raised by another 18 PCCLs.

The PCT Managers

4.10. Response Rates:

A total of 299 questionnaires were sent out and 181 were returned giving a response rate of 61%. Although the questionnaire was meant for Chief Executives (CE), only 37 (20%) were completed by a CE. 144 (80%) were completed by other PCT representatives, with a range of job titles (Table 9). Most of the respondents who were not the Chief Executive of the PCT indicated that they were able to respond to the questions either because they worked closely with the PCCL, were the PCT cancer lead, were the PCCL's line manager, or were involved in the appointment of the PCCL.

Table 9: Areas of responsibility in job titles of respondents to PCT manager questionnaire

Area of responsibility	No.
Public health	53
Commissioning	20
Service development	13
Clinical development / services	8
Cancer services	8
Health	8
Modernisation	7
Strategy	3
Finance	3
Primary care	3
PEC	2
Clinical governance	2
Miscellaneous	9
Total	139

4.11. PCT Characteristics:

The population of the responding PCTs ranged from 73,770 to 340,000 with a mean of 170,011. The mean number of practices per PCT was 30. The mean number of GPs per PCT was 106 (Table 10).

A total of 28 (16%) PCTs described themselves as inner city; 46 (26%) were urban; 9 (5%) were suburban; 25 (14%) were rural, and 68 (38%) described themselves as mixed.

Table 10: Characteristics of the PCTs

Characteristic	No.	Mean	SD	Median	Lower quartile	Upper quartile	Minimum	Maximum
Population of PCT	175	170,011	62,916	158,000	118,000	214,000	73,700	340,000
Number of practices	172	30	16	26	18	35	8	104
Number of GPs	153	106	52	95	68	140	10	284

PCT strategic objectives: The strategic objectives identified by the PCT managers were variations of those that would be expected as their three principal functions: improving the health of the population; developing primary and community services; commissioning a range of community and hospital services. [14] In addition, a number identified achieving financial balance as a key objective.

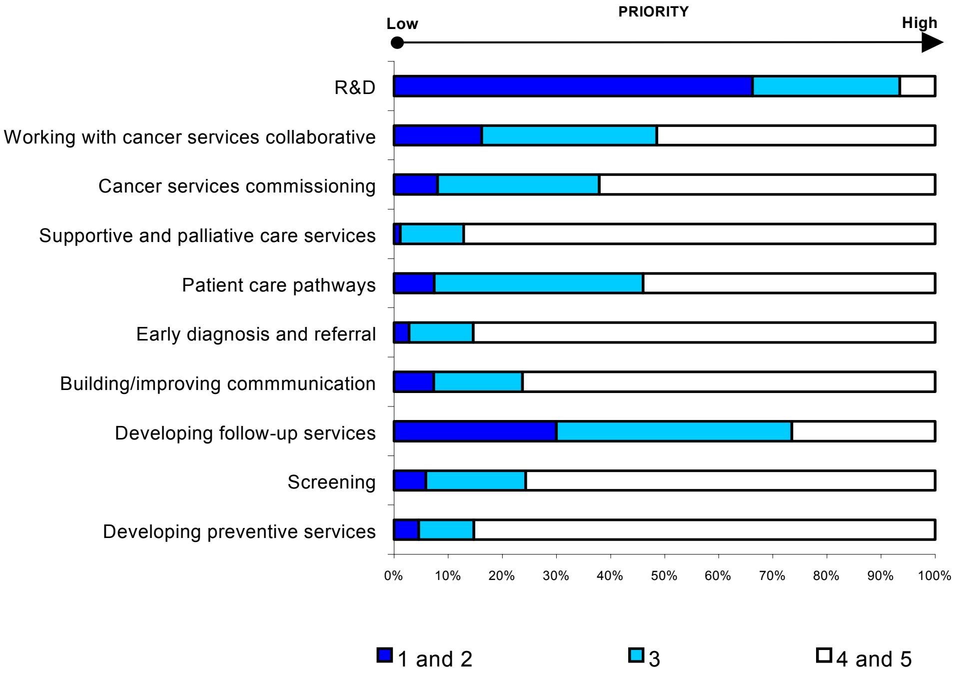
PCCL influence on PCT strategic objectives: When asked whether the setting up of a PCCL post had influenced the strategic objectives of the PCT, if at all, almost one third of respondents were of the opinion that it had not. Aspects of the PCTs' work that PCCLs were credited with influencing were primarily in prioritising primary care cancer at all levels, and promoting national and local strategies. Service developments and improvements were also mentioned as areas influenced by the PCCLs.

Cancer related issues being focused on by the PCTs: Respondents were asked to give a list of issues a score from 1 to 5 (where 1 = low priority and 5 = high priority). The main focus was on supportive and palliative care, developing preventive services and early diagnosis and referral. Research and development and developing follow up services were given the lowest priority (Figure 8).

4.12. The PCCL in the PCT:

Vacancies, turnover and time input of PCCLs: A total of 151 (83%) of the PCTs had a PCCL in post. The median length of time the PCCLs had been in post was 24 months and for those PCTs in which the post was vacant, the mean length of time of the vacancy was 9 months. 80% of the PCTs had one PCCL in post (131/164), 28 (17%) had 2, three had 3, one had 4, and one had 5 (Table 11).

Figure 8: Cancer focus in the PCTs



A total of 148 responded about professional background: 109 (74%) PCCLs were GPs, 32 (22%) were nurses, and 7 had 'other' professional backgrounds. The mean number of hours per week worked by the PCCLs was 5 hours. Two-thirds (94/142) of the respondents felt that the PCCL did not have sufficient time to achieve all that was required of them.

Table 11: The PCCL in the PCT

	No.	Mean	SD	Median	Lower quartile	Upper quartile	Minimum	Maximum
Time PCCL has been in post (months)	142	21	7	24	18	24	0	36
Time post has been vacant (months)	34	9	10	6	2	12	0	36
Total numbers in post	164	1	1	1	1	1	1	5
Number of PCTs per PCCL	152	1	1	1	1	1	1	9
Number of hours per week employed	158	5	3	4	4	8	1	37

In terms of the support provided to the PCCL by the PCT, half of the managers said that they provided secretarial support, two-fifths provided admin support and a third provided other support (Table 12).

Table 12: Support provided by the PCT to the PCCL

	Secretarial support from PCT		Admin support from PCT		Other support	
	No.	%	No.	%	No.	%
Yes	68	49	59	43	42	33
No	70	51	78	57	86	67
Total	138		137		128	

Key areas of work: PCT managers were asked to identify the key areas of work for their PCCLs. Almost one third of respondents identified palliative care and GSF implementation as their key target area. This was followed by communication/ raising the profile of cancer services and liaising with the Cancer Network. Other areas mentioned were referrals, audit/Baseline Assessment, care pathways, prevention/screening, attending meetings, implementing the Cancer Plan and commissioning.

4.13. How the role of the PCCL in the PCT has developed:

Key Achievements: The key achievements of PCCLs identified by PCT managers were similar to those the PCCLs themselves highlighted, although the emphasis was different. Raising the awareness of cancer at all levels was a major key achievement as was developing relationships, communication and promoting primary care. Progress in palliative care/ GSF was the major practical issue identified by PCT managers as a key PCCL achievement. This was followed by specific local service issues and developments in the two week wait agenda. Baseline Assessment and out of hours palliative care were mentioned by only a few PCT managers, in contrast to the PCCL responses. Setting up of, membership of and chairing groups were also mentioned as achievements. It is interesting that the PCT managers made no reference to PEC membership in this context. This is perhaps unsurprising and highlights the gap between PCCLs and PCT managers in facilitating the PCCL role.

Factors associated with key achievements: The PCT managers placed a different emphasis on the factors associated with key achievements than the PCCLs. The most frequently mentioned factor was the personal skills that the PCCL brought to the post. It is perhaps not surprising that the PCT managers gave greater priority to the PCCLs' personal attributes than did the PCCLs themselves, since most people are reluctant to praise themselves. This could be due to managers personalising the role rather than viewing it structurally. On the other hand the managers identified more organisational barriers to achievement than did PCCLs. Those personal attributes most likely to be mentioned were commitment, enthusiasm and interest.

The next most important factors were the support that the PCCLs received from colleagues at all levels, including the PCT, Networks and Macmillan, and the relationships that they had been able to develop to promote teamworking. Local knowledge and clinical credibility were also identified as being important in allowing PCCLs to develop their role more easily. For many, being a GP, and hence being a respected peer, was highly regarded.

Some identified the specific support given by the PCT, and how public health involvement had contributed to the PCCLs being able to achieve some successes. Dedicated time was also an important factor, as was funding. Only four respondents commented that being a PEC member was significant, in contrast to the importance given to this by the PCCLs.

Things that had worked less well: In common with the PCCLs, the PCT senior managers identified the level of engagement as something which had not worked particularly well. Again, GPs were seen as the most difficult group to engage. Some PCT managers thought that PCCLs had not worked strategically in covering the agenda or co-ordinating services in the manner that had been expected. For some, PCCLs had not become sufficiently involved in commissioning, palliative care or Baseline Assessment; for some finance had been problematic.

Barriers to achievement: The PCT managers overwhelmingly identified lack of time as the major barrier encountered by the PCCLs. This was followed by attitude, commitment and relationship difficulties, which also featured highly for the PCCLs themselves. This manifested itself particularly in a lack of understanding of the role from consultants and GPs and sometimes a resistance to change. Large numbers of organisational barriers were flagged up by the PCT managers, in contrast to the findings from the PCCLs. These included a lack of capacity, competing priorities and poor infrastructure. Lack of support at all levels was also highlighted, as was a lack of funding. A few PCT managers mentioned that some personal attributes of the PCCLs acted as barriers to achievement.

Priorities for the future: A large number of different priorities for the future were identified by the PCT managers, foremost of which was continuing to develop palliative care and the GSF. This was followed by improving services generally and developing strategy. Continuing to develop and improve relationships was also considered to be an important priority. Screening, prevention and health promotion also featured highly as did the development of patient pathways. Many simply commented that they would continue in the same way, and there were some respondents who did not know what the PCT priorities were, or they had not been agreed.

Specific focus of the PCCL: Just over half of the PCCLs had focused on a specific aspect of cancer services since they took up their post (Table 13). For those who said that their PCT's PCCL had a specific cancer focus, by far the most likely aspect was palliative care. A few also identified primary care services, screening/prevention and referrals as the PCCL's focus.

Board membership and attendance at meetings: A third of the PCCLs were a member of the PEC, and a tenth were a member of the PCT board. Two-thirds attended PEC meetings and a third attended the PCT board meetings. The majority attended Cancer Network meetings and other meetings (Table 13).

4.14. Collaboration:

Extent of contribution to the development of the Cancer Network: There were links between the PCCL and the Cancer Networks. 87% of PCCLs represented the PCT at the Cancer Network, and two-thirds helped in developing service delivery plans (Table 14).

Table 13: Aspects of the PCCL role

Aspects of PCCL role	Yes		No		Don't know		Total
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**
PCCL focused on a specific aspect of cancer services?	74	53	64	46	1	1	139
PCCL is a member of PEC	49	33	100	67	0	0	149
PCCL is a member of PCT board	17	12	130	88	0	0	147
PCCL attends PEC meetings	86	60	57	40	1	1	144
PCCL attends PCT board meetings	39	30	92	70	1	1	132
PCCL attends Cancer Network meetings	130	88	15	10	2	1	147
PCCL attends other meetings	117	85	21	15	0	0	138

Contribution to raising the standard of care in the PCT: Table 14 shows that the majority of PCCLs were considered to have contributed to raising the standard of cancer care in the PCT. PCT managers were of the opinion that PCCLs had raised the standard of cancer care, primarily by their efforts in palliative care and GSF. Other areas were identified as referrals, raising the profile of primary care cancer services, improving relationships and communication by means of education and training sessions for professionals, and by audit and improving standards.

Table 14: Extent of collaboration

	Yes		No		Don't know		Total
	No.	%	No.	%	No.	%	No.
Contribution to development of cancer network:							
Represents PCT	130	87	15	10	4	3	149
Developing service delivery plans	99	68	36	25	11	8	146
Contributed to raising standards of cancer care in PCT?	130	92	10	7	2	1	142

4.15. The PCCL Role:

Personal attributes of PCCLs: Table 15 sets out the most important attributes identified by the PCT managers as necessary for PCCLs for their role. The most important were communication skills, having the respect of colleagues, knowledge, enthusiasm and commitment. These should be compared with those identified by the PCCLs (Table 5). Choices were similar from both groups of professionals.

Patient awareness of PCCLs: Only 17 (10%) PCT managers thought that patients would be aware of the existence of PCCLs. The view was that the only patients who were likely to have heard of PCCLs were those who were members of user groups. The role was seen as a 'behind the scenes' strategic one with no direct impact on patients.

How the PCCL role has changed over time: Of those who responded, the largest number said that the role had not really changed. Others indicated that the PCCL had become more involved and integrated into the team or that the role had become more focused. Others thought that the PCCL role had expanded and become more strategic.

Contribution of the PCCL role to the improvement of patient experience of local services: PCT managers identified palliative care as the main area where PCCLs had an impact on improving patient experience. Other areas were generally improved services, strategic developments and improved referrals and pathways. Some others were unable to identify any improvements or were unclear about the situation.

4.16. The Future:

Continuation of the PCCL role: 85% of PCT managers felt that the PCCL role should continue; 65 (40%) thought that the ideal number of sessions should be the same as now, with 89 (55%) thinking more sessions were required. Only 3 (2%) thought that the number of sessions should be reduced, and 6 (4%) did not know. 59 (34%) knew of a decision about future funding having been made. Of these, 49 (84%) were to fund at the current rate. However, 4 (7%) were to increase funding and 2 (3%) had decided to withdraw funding.

Impact of the new GMS contract on PCCLs: In contrast to the views of the PCCLs, almost half of the PCT managers who responded either did not know or thought that the new GMS contract. [6] would have little or no impact on the work of the PCCLs. About a quarter thought that the new contract would enhance emphasis on cancer within the PCT, and hence promote the PCCL role. In particular, PCCLs were expected to have an impact on enhanced services and to be required to contribute more to the development of cancer registers and to support practices in achieving their quality standards. A smaller number of respondents raised concerns about the lack of points available for cancer services in the quality framework, and that practices would be likely to concentrate their efforts elsewhere. Some thought that it could become even more difficult to engage GPs as a result. PCCLs would, however, have a role in re-emphasising the importance of primary care services. A few thought that there would be workload implications for PCCLs, but only three respondents expressed concerns that PCCLs would have even less time to devote to their PCCL role.

Table 15: Important personal attributes for PCCLs

Attribute	Number of times suggested
Communication skills	51
Respect of colleagues	43
Knowledge	43
Enthusiasm	28
Commitment	23
Able to think strategically	21
Inter-personal skills	19
Clinical leadership	16
Assertiveness	15
Networking ability	13
Dedication/persistence	12
Influencing skills	11
Broad view of service	10
Time issues	9
Persuasiveness, teamworker, passion	6
Resilience	5
Hard worker	4
Managerial ability	3
Access to public health expertise, patience/tolerance, patient focused, diplomacy, objectivity, interest	2
Experience, flexibility, non-judgmental, legitimacy, able to be a primary care voice, effective, faciliatator, NHS focus, listening skills, collaborative, negotiator	1

Changes to improve the effectiveness of the PCCL role: The change most likely to be suggested to improve the effectiveness of the role was to increase the amount of time the PCCLs were able to devote to it. This was coupled with comments about the lack of clarity of the role and how ensuring that it's purpose was understood by all involved would help to improve its effectiveness. Having adequate support in place for the PCCLs was also regarded as important, as was ensuring the role is acknowledged by PCTs as having a significant contribution to make. Some commented on the importance of appropriate infrastructure to support the PCCL. This could come from the Network, Macmillan and secondary care as well as from the PCT. Others thought that the PCCL role might become more effective if it were to be further developed, focused and recognised as a key role for the PCT. Training and teamworking were seen as important. Additional resources were recognised by a few respondents as being required to increase the effectiveness of the role. A similar number felt that nothing was required to increased the effectiveness of the role. Linking with other organisations – the Modernisation Agency, the Network, practices, Macmillan, commissioners etc, was advocated by some. Finally, closer links with the PEC were suggested by a few respondents.

The scope of the PCCL role: Views of the PCT managers about the scope of the PCCL role could be divided into four groups: positive comments about the role; its significance in awareness raising; the lack of clarity and the confusion associated with the role; and the fact that the expectations of the PCCLs were too broad.

Some thought that the role was excellent and could act as a model for other services. Its value was, however, thought to be very dependent on the right appointment. It also sometimes lacked support and accountability. The role had been useful in raising awareness of cancer issues more widely. There were some comments about the lack of clarity and there being confusion about what was expected of the postholder. A large number of respondents thought that the role was too broad and would benefit from a more focused approach.

5. The Costs of the PCCL Scheme

The postal surveys to PCCLs and PCT managers included questions about the costs of the PCCL scheme and the results are set out in this Section.

Latest Annual allocation of funds for PCCLs: From the PCT managers' responses, the latest annual allocation of funds to the PCTs to support the PCCLs was provided and the results are set out in Table 16. According to the 133 PCT managers who responded, 37 had received £5000; 28 had received £7000; 16 had received £7500; 20 had received £8000 and 14 had received £10,000. The variations occurred as a function of the population size of the PCT. Table 16 also shows the responses from the PCCLs to the same question and very similar results were obtained. It is important to note that some PCT managers responded whilst their PCCLs did not and vice versa so that the results are not directly comparable.

Table 16: Latest Annual allocation of funding to the PCT from the Department of Health for the PCCL

Latest Annual allocation (£)	**PCT managers' response** n (%)	**PCCLs' response** n (%)
0-2000	2 (1.5)	1 (0.8)
2001-4000	1 (0.75)	0 (0%)
4001-6000	42 (31.6)	19 (15.8)
6001-8000	64 (48.1)	78 (65.0)
8001-10,000	16 (12.0)	1 (14.2)
10,001-12,000	2 (1.5)	1 (0.8)
12,001-14,000	2 (1.5)	2 (1.7)
14,001-16,000	2 (1.5)	1 (0.8)
18,000	0 (0%)	1 (0.8)
20,000	1 (0.75)	0 (0%)
75,000	1	0 (0%)
Total	133	120

Use made of the financial support for PCCLs: The use made of the financial support to the PCT for the PCCLs, as estimated by the PCT managers, is set out in Table 17. The majority used the funding to support PCCL sessions; a sixth funded support staff, and 13% used it for other functions. In terms of the resources provided, one third of PCCLs were provided with office space and a third with a computer. In addition, one third were paid travel expenses and two thirds had support for training costs. However, the latter is provided by Macmillan and suggests some confusion amongst respondents about the source of funding.

Table 17: PCT managers' estimates of the use made of the financial resources provided to PCCLs

	Yes		No		Don't know		Total
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**
Funding							
Supports PCCL sessions	152	93	7	4	4	2	163
Supports staff	21	16	104	78	9	7	134
Other	17	13	109	81	8	6	134
PCCL provided with:							
Office	42	31	93	68	1	1	136
Computer	46	34	88	65	2	1	136
Travel costs	100	72	31	22	8	6	139
Training costs	97	69	31	22	12	9	140

The PCCLs' response to the same question are set out in Table 18. Results show similar trends with the PCCLs identifying additional items, including clinic facilities.

Table 18: PCCLs' estimates of the use made of the financial resources provided

	Yes		No		Don't know		Total
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**
Funding							
Supports PCCL sessions	135	87	7	5	13	8	155
Supports staff	36	26	71	52	30	22	137
Supports office costs	25	18	83	60	30	22	138
Other support	31	25	62	50	31	25	124
PCCL provided with:							
Office	32	18	148	82	0	0	180
Computer	43	24	138	76	0	0	181
Travel costs	111	61	70	39	0	0	181
Training costs	88	51	83	48	0	0	171
Clinic facilities	8	5	161	95	0	0	169
Secretarial support	53	31	120	69	0	0	173
Admin support	72	41	103	59	0	0	175

Other	17	20	68	80	0	0	85

Additional resources provided annually by the PCT:

Financial resources: Table 19 shows the additional financial resources identified by the PCT managers as provided for PCCLs from PCT funds, over and above the allocation from the Department of Health. Most PCTs provided relatively little additional support to their PCCLs. In fact 37 (41%) of the 90 PCT manager respondents said that they provided no additional financial support and one provided just £50 per year. 73 (81%) of the PCCL respondents said that they received no additional financial support (Table 19).

Table 19: Additional annual allocation of funding from the PCT for the PCCL role identified by PCT managers

Annual allocation (£)	PCT managers' response No.(%)	PCCLs' response No. (%)
0-2000	50 (6)	78 (87)
2001-4000	12 (13)	4 (4)
4001-6000	14 (16)	3 (3)
6001-8000	5 (6)	0 (0)
8001-10,000	6 (7)	1 (1)
10,001-12,000	0 (0)	1 (1)
12,001-14,000	0 (0)	0 (0)
14,001- 16,000	0 (0)	2 (2)
25,000	1 (1)	0 (0)
27,000	1 (1)	0 (0)
28,000	0 (0)	1 (1)
40,000	1 (1)	0 (0)
Total	90	90

Resources provided in kind: As well as the funding allocations described above, additional support 'in kind' was also given. This was provided, according to the PCT managers, in the form of secretarial, administrative or support from senior managers and was essentially difficult to quantify since it was provided on an 'ad hoc' basis, as and when required. It was simply just another task for the support staff member. A few respondents did attempt to quantify the additional support provided. This usually amounted to one or two hours per week of secretarial, administrative or managerial support, but individual PCCLs rarely received all three. A very few received more support: for example, one estimated £15,500 per year for managerial support, and another estimated 18 hours a week of similar support, but this was rare. Two respondents identified public health support to the PCCL.

In general then, possibly, a mean of 2 hours per week of support would amount to approximately £2000 per year in financial terms per PCT.

From the PCCLs, the most likely response to the question about the amount of support in kind provided to them was 'none', in contrast to the PCT managers, none of whom gave this response. Beyond this, secretarial, administrative or managerial support amounting to a mean of 2 hours per week was mentioned, confirming the PCT management responses. 'Ad hoc' support, or support 'as required' was also mentioned. A large number of PCCLs pointed out that they received no additional support, the post being absorbed as part of their role within the PCT, or because they were a PEC chair or member. Some mentioned the Macmillan support they received for training and travel. For some the funding was used as backfill. Finally, some noted that they frequently used their own resources – computers, practice staff and offices.

A number of PCT respondents also pointed out that some PCCLs received no additional support for being a PCCL: it was simply absorbed as part of their existing role. This was most likely to be the case for the Nurse PCCLs. Another group for whom this arrangement also applied was for those PCCLs who also served as the Director of Public Health for the PCT or who were employed on a full time basis by the PCT. Some, particularly the GPs, used any funding they received for backfill.

6. The Macmillan Support Programme (MSP)

The contents of this section are based on the responses of the PCCLs to questions in the postal survey, face-to-face interviews with the Macmillan Support Programme Providers (MSP Providers) and responses to questions by the interviewees in the case studies.

6.1. The Overview:

The Macmillan Support Programme offered: individual learning and support; collective learning and support; and Central Programme Support which included access to topic based materials and toolkits (MSP 'Working Briefs'); a telephone 'help line'; and website based information. The tables and findings set out below are taken from the PCCL postal survey results.

Awareness of the Macmillan Support Programme (MSP): Knowledge of all aspects of the Macmillan Support Programme for PCCLs was almost universal with only a small number being unaware of some aspects of the programme (Table 20).

Table 20: Awareness of the Macmillan Support Programme

Aspects of Programme	Yes		No	
	No.	**%**	**No.**	**%**
Individual learning opportunities	155	85	28	15
Collective learning set events	177	97	6	3
Cancer network events/activities	168	91	16	9
Regional conferences	175	95	9	5
PCCL Website	165	90	18	10
Support materials	163	89	21	11

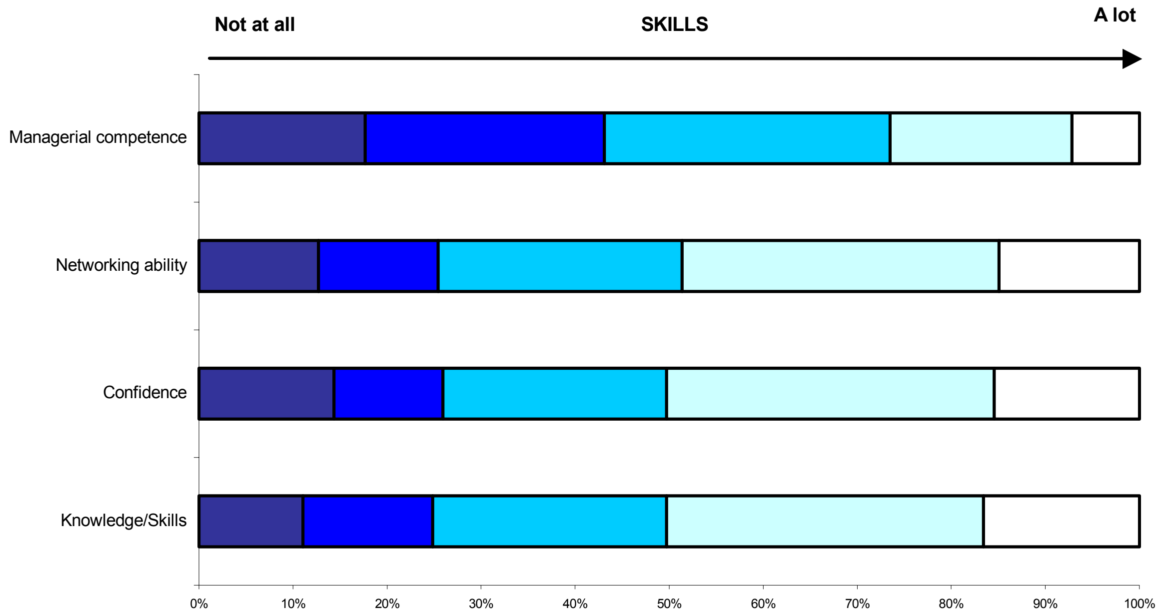
Use of the Macmillan Support Programme: Table 21 shows that the most widely used aspect of the MSP was the Collective Learning Set (CLS) opportunities. Cancer Network events were also widely supported. Although the PCCL website was not used frequently by many PCCLs, it had been used occasionally by a majority.

How the Macmillan Support Programme has contributed to PCCL skills: Contribution of the Macmillan Support Programme to PCCL development was assessed using a scale of 1 to 5 (where 1 = not at all and 5 = a lot). Of the options provided, contribution to knowledge/skills and networking abilities were most likely to be selected and managerial competence least likely (Figure 9).

Table 21: Use of the Macmillan Support Programme

Aspects of the MSP	Frequently		Occasionally		Never	
	No.	%	No.	%	No.	%
Individual learning opportunities	36	20	59	33	86	48
Collective learning set events	91	50	55	30	38	21
Cancer network events/activities	68	37	84	46	32	17
Regional conferences	41	22	97	52	47	25
PCCL Website	16	9	115	62	54	29
Support materials	41	22	108	59	35	19

Figure 9: Contribution of the Macmillan Support Programme



Most useful aspects of the Macmillan Support Programme: The aspect of the Macmillan Support Programme found particularly useful to PCCLs was the opportunity the CLSs provided for networking with others, sharing successes and problems and learning from others (129). Written information was commented on positively by 13 respondents, as was help with Baseline Assessment (7). Just six noted that they had not used the programme.

Additional training needs identified: A total of 51 PCCLs considered that the programme was about right. Where needs were identified, they were frequently on topics already covered by the programme including information technology (IT) (12), negotiating with the PCT (5), management (4) and further information (4), but numbers were small, indicating an overwhelmingly satisfied group of clients.

Feedback: A total of 44 (24%) respondents had regularly used the MSP to feed back details of local initiatives to other PCCLs. A further 81 (45%) had done so occasionally and 55 (31%) had never done so.

Frequency of use of personal development opportunities: Table 22 shows the frequency of personal development opportunities (PDP) use by PCCLs. Most had used these opportunities once only and four mentioned that time restrictions made this very difficult.

Table 22: Frequency of use of personal development opportunities

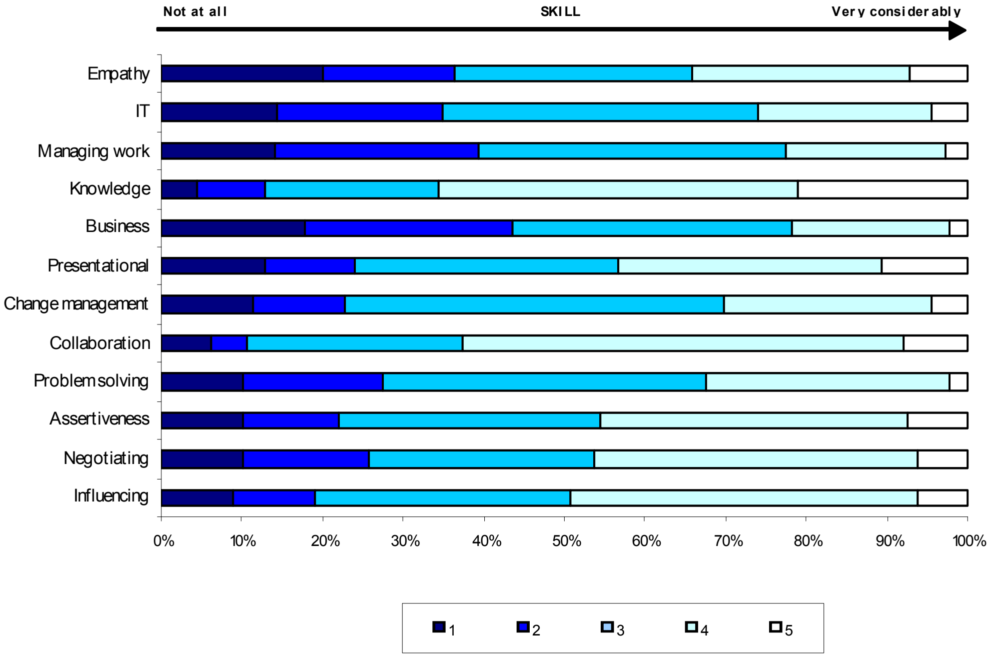
Number of times used	Number of PCCLs
Once	26
Twice	11
Three times	5
Four times	2
Time restricted	4

Additional cancer education/management undertaken: A total of 75 (42%) PCCLs indicated that they had undertaken cancer management opportunities other than the MSP. They had undertaken courses and attended national and local conferences. Some of the courses attended were on pain symptom control, change management, breast and lung cancer, bereavement, leadership, care pathways, palliative care, presentation skills, communication, IT and oncology. Five noted diploma or degrees in breast care, palliative medicine and primary health care. Some had lectured to GPs, nurses and PCTs, one had become national clinical lead with the Cancer Services Collaborative and one was project manager for the Cancer Network.

Skills improvement since becoming a PCCL: PCCLs were asked to rate whether or not they felt their skills had improved since becoming a PCCL on a scale from 1 to 5 (where 1 = not at all and 5 = very considerably). The results are set out in Figure 10 and show that knowledge and collaboration abilities were identified by the PCCLs as the skills that had improved the most since taking up their post.

Of the skills listed, PCCLs identified improvements in influencing (25) and negotiating (21) as the areas most likely to be attributed to the MSP. Other skills noted were knowledge of cancer pathways (13), assertiveness (13), collaboration skills (13), presentation skills (11) and change management (11). However, a substantial number of respondents (54) were unable to attribute any of their skills improvements listed to the MSP. Of these, two had only recently taken up their PCCL post, six learned on the job rather than via specific training and five had received no training at all.

Figure 10: Improvement in skills



6.2. The Macmillan Support Programme Provider Perspective:

Background: Each of the three Macmillan regions of England has an MSP Provider, charged with delivering the collective learning sets (CLSs) and individual learning programmes. Each MSP Provider delivers the support programme within a clearly defined overall framework, objectives and reporting/monitoring mechanisms but with some local flexibility on the style and method of delivery. One of the MSP Providers had the contract for the overall design of the programme delivered by Macmillan, as well as for the elements described above. Within each programme the PCCLs are usually divided into CLS groups. The groups meet on a regular basis to discuss topics of interest and gain group/peer support, and there are also telephone and email helplines, should they be needed. The CLSs tend to be PCCL led, although similar issues have been raised in all three areas e.g. commissioning, Baseline Assessment, finance, management and IT skills.

The programme ran from October 2001 to March 2004 with the design work being accomplished before then. The three MSP Providers generally worked independently of each other but with broadly similar programmes appropriate to PCCLs' needs and within a common framework. Contact between the three groups was intermittent, although more had taken place in the early stages of the programme. Although the programmes were similar, based on the same curriculum, mode of delivery differed. The three MSP Providers operated within a clear reporting framework for overall programme monitoring.

The following sections summarise the findings from face to face interviews undertaken with MSP Providers and telephone discussions with Macmillan facilitators.

Running the Programme: PCCLs had a major input to the learning sets which tended to be customised to suit their needs. What they wanted in the later stages of the programme was less 'content' and more 'process' – the opportunity to come together and talk about what was happening and where they could learn from each other's successes and failures. It was thought that they learned as much from each other as from the MSP Providers or the presentations. Macmillan had done a considerable amount of forward thinking about the content of the programme and seems to have hit the right note. The CLSs were designed around what people needed and wanted – they are very highly regarded and PCCLs get a considerable amount out of them.

A major advantage of MSP Providers being independent of the NHS meant that PCCLs could discuss their problems or difficulties without fear of anything being reported back to the PCT.

Would the MSP Providers have done anything differently? There was a view that reporting back to Macmillan should change, although it had not been onerous. However, PCCLs not turning up, being difficult or impossible to contact, had been a problem, and a decision had to be made to stop chasing those who had not responded. It was felt that if the PCCLs had had to competitively apply for their post they would have been more receptive to the MSP- in many instances, there was no choice in becoming a PCCL.

In one MSP region, the individual learning programmes didn't really take off since many PCCLs didn't really engage at this level, preferring the CLS. Personal development plans (PDP) were a difficult concept for GPs but it was essential to get PCCLs to think about what outcomes they wanted. However, participation increased during the course of the programme. PCCLs tended to panic about form filling, especially with the Baseline Assessment, and the MSP Providers had to lead them through the process. GPs, Nurses and Pharmacists approached the situation very differently; in some ways Nurses may have found things easier than GPs because they are more task focused, but most experienced some panic initially and needed leading through.

Macmillan identified possible contenders to act as support providers from outside the NHS to allow confidentiality. There is no reporting back to Macmillan or the Department of Health about individual discussions.

Achievements and Problems: The MSP Providers identified success in getting PDPs off the ground, something which many PCCLs found difficult. There was also the view that PCCLs had improved their influencing skills and confidence, and that there had been a shift in thinking and behaviour. The most successful aspects of the MSP were the CLSs, as noted elsewhere in this report. Without them, many PCCLs would have floundered. Although cancer was the obvious choice for a primary care lead initiative, it was considered as a possible model for other diseases, for example, diabetes.

A number of problems, also identified elsewhere in this report, were also noted by the MSP Providers. One was that when the initiative was first set up it coincided with a time of considerable upheaval as PCGs became PCTs, leaving little time for PCCLs. Also, the assumption had been made by the MSP Providers that PCCLs had applied for and been interviewed for their posts, but initially this was not always the case, perhaps reflected in initial high turnover rates. PCTs also tended not to be aware of what was happening, although this has since improved. As one MSP Provider commented:

> *'The leads that work best are those that get the most support and structure.'*

Those that worked the best also had links to a designated PCT manager. The issue of deprived areas was also raised.

> *'PCCL stuff works well in areas where you expect things to work well, but in areas which are more deprived, where there's social exclusion…I just wonder how well it works?'*

Several times, it was suggested that perhaps such areas required something more mundane, particularly where GPs were in short supply.

> *'Deprived inner city health care isn't really ready for this kind of fairly sophisticated plug-in. Poorly developed primary care needs enough GPs to start with.'*

Of course, the impossibility of the job description in relation to the amount of time available was raised. In terms of the MSP itself, PCCLs did tend to turn up against the odds, although keeping up the momentum was sometimes difficult.

The website was not widely used, partly because GPs, initially, were unused to email and tended deal with it in the same way as postal mail – it simply piled up and was not prioritised. This was made worse by anything involving cancer landing on the PCCL's desk.

Attendance: The average attendance at CLS sessions was 50-60%, which was somewhat at odds with the general view from PCCLs that this was the part of the MSP that they appreciated the most. However, a number of PCCLs did comment that they found regular attendance difficult, timewise. When first appointed PCCLs tended to be enthusiastic about the programme, but this could drop off over time as some felt they had got all they could from the programme; others just 'ticked over'.

The MSP was voluntary and there were a few PCCLs who wanted nothing to do with it, some vehemently. However, in one area in particular, most PCCLs had been there from the start, the motivation being that they got a lot out of meeting each other.

It was noted, significantly, that some PCCLs were not doing much, but this was less related to location (city/rural) than to PCT dynamics, an observation in accord with others noted elsewhere in this report. Whether PDPs actually made a difference to the success or not of PCCLs was regarded as debatable.

Characteristics of Success: As one MSP Provider commented:

It's like a cottage industry but it works.'

The CLSs were regarded as particularly good at inducting new PCCLs and in providing training in negotiation skills and assertiveness, though there was some debate about whether the later is trainable. Some additional factors thought to be associated with success were having the vision to want to see things done differently for cancer care i.e. being able to provide strategic leadership. GPs tended to be comfortable with being a 'clinical champion', but less so at a political level. PEC membership was again considered to be important, but not if the PCCL had to bully their way in. As one facilitator put it in response to a question about whether it is important to be on the PEC Board:

'Absolutely. Or be married to someone who is. That helps!'

It could be a mixed blessing. Nurses sometimes felt 'conned' into the job, as being 'good for their CV' but it could be a good career progressor for some, who then tended to move on.

Networks: Relationships between the MSP Providers, PCCLs and Networks had not always been easy, possibly caused by a lack of clarity about the Networks' roles and their emphasis on the secondary/tertiary sector. Misunderstanding had arisen, for example where Network management expected to attend PCCL meetings, but which PCCLs considered inappropriate. In some instances, Networks were informed about the presence of PCCLs but did not respond. PCCLs had sometimes given presentations at Network meetings but were of the view that sometimes *'they look like they are listening but they won't hear it.'* There was a feeling, sometimes, that PCCL presence at Network meetings was tokenistic, they lacked power and were not taken seriously. On the other hand, Network staff could be daunted by primary care with concerns about large numbers of GPs who could be difficult to control. However, Track 3 of the Macmillan Support Programme had facilitated communication with, and commitment from Networks.

Future provision: The general view was that the PCCL initiative should continue but perhaps not in the same format (which is what is planned by Macmillan). One view was that the programme was initially designed as a PDP but needed to move into being a geographically based development programme, together with a start up package for those coming in.

The scheme had been relatively successful in getting PCCLs up to speed on cancer and now needed to move on. The real achievement was in bringing groups together to talk and make links. It was noted that PCCLs have a vast array of informal knowledge that is difficult to pass on except by social interaction, and it would be a shame to waste it. The transitional hiatus that will be created as the funding system changes could be a problem and set things back for a while.

'It has opened the minds of the PCCLs.'

Some suggestions for the future of the MSP included:

- Taking a GP from each Network and giving them a special programme to develop future leaders
- Using existing chat rooms rather than the dedicated website
- Targeting more, rather than the current 'broad brush' approach.

Finally, one facilitator summed up the situation succinctly:

'It felt like hanging on to the tail of a tiger but it's been fun.'

6.3. The View from the Case Studies:

The following Section sets out the findings from the Case Study analysis relating to the MSP.

Training needs: Three topics are of interest in this regard: first, the training needs of PCCLs; secondly, skills they have developed through performing the role; and thirdly, views about the MSP. Needless to say, these overlap.

The first thing to note is that most PCCLs thought that they did, or still do, need some training for the role. A small number felt they were experienced enough already, particularly the few who had chaired PCTs or PECs, or had been through management development programmes. In contrast, a PCCL who was an experienced GP described how it felt to be thrown in at the deep end:

> *'Realistically, it probably took six months before I had any idea of what I could do and … where all these groups with long names were coming from - and they were always reforming and forming and then disbanding. It was quite confusing and very frustrating.'*

Being *'left out in the wilderness'* was another description. The most common experience was expressed by a PCCL who thought it took him a year to start building working relationships:

> *'I think you really need to hit the ground running, but a lot of PCCL's have gone by the wayside and I think it's because they couldn't cope with the workload and the amount to be learned … I started with knowing a lot of the people and that helped a great deal, but I still found there was loads more that I didn't know. I spent a good chunk of the first year learning who the people were. You only start getting dividends when you've formed those relationships, and they begin to understand what you're trying to do and realise that you're looking for joint solutions.'*

Given the amount of organisational change at the time they were introduced, it could hardly have escaped anyone who thought about it that many PCCLs would struggle to find their feet. Nevertheless, no-one that we interviewed had any kind of structured induction. In fact, we came across only two or three cases where a Chief Executive or other Director sat down with the PCCL and discussed how they would approach the remit. Macmillan did produce an information pack for PCCLs. Some of them mentioned it as having been very helpful; as many others said it was no help, and most that we spoke to did not mention it at all. The other basic problem was that of clinicians taking on a quasi-managerial role without, in most cases, any management training.

Drawing together various comments, the core training needs were as follows:

- The PCCL remit, how it relates to other roles, and how Networks, Cancer Boards and Cancer Action Groups (or equivalent) all inter-relate
- Organisational understanding: the structure and workings of PCTs, their relations with the rest of the NHS and other agencies
- Commissioning processes and local budgeting, overall and specifically in regard to cancer services and decision-making forums
- Communication, analytical, decision-making, influencing and negotiation skills relative to the various contexts in which PCCLs need to be effective, and a grasp of how to build capacity for change
- Awareness of care pathways and key issues affecting the development of cancer services in primary, secondary and tertiary care.

The choice of words in relation to knowledge of cancer was meant to tread a line between, on the one hand, those who maintained that a PCCL must have hands-on clinical knowledge of cancer, and, on the other hand, those who believed that a PCCL might not need that clinical background but must to be able to come to grips with the differing views about service improvement. The first is essential for cancer service delivery, but others are involved in that apart from the PCCL. The second is a direct prerequisite for any PCCL to fulfil their function.

There was a great deal of concern that PCCLs must have credibility within their own PCTs, and must not be regarded as ciphers in other decision-making forums, which are often dominated by hospital specialists. If credibility is associated with clinical expertise, first and foremost, it is hard to see how many people can qualify, given that few people in primary care have in-depth knowledge of cancer. It seems much more to the point that any PCCL will struggle to perform the role well if they have little or no training in the five areas listed.

However, we are not arguing for a 'sheep dip' approach to PCCL training. Rather, we would treat that list as a kind of outline prospectus against which individual PCCLs' training needs can be identified so they can be met on a targeted basis. This seems much more likely to happen if there is some consolidation, with fewer PCCLs operating across PCTs with infrastructural support and with dedicated funding for professional development.

Skills developed:

> *'I've got more assertive - able to negotiate without getting unpleasant, whereas my experience with PCGs was the only GPs you saw putting a point across seemed to be quite unpleasant and aggressive about it … I've also got better at financial analysis … and [as a result] I've actually got more cynical … because the hospitals are very good at putting a certain gloss on things and presenting something as a fait accompli.'* (PCCL)

> *'She has got better at being a leader within a team … She has learned that you don't get all your own way by stamping your feet and shouting, but collaboratively.'* (Chief Executive, referring to another PCCL)

> *'both of them have developed their leadership skills. They've also developed a much stronger network than they would have had they not been cancer leads.'* (DPH – PCCL is a job-shared by a nurse and GP)

> *'I had quite a lot of experience of management as far as general practice is concerned, having been PCT chair … I have picked up quite a lot of clinical skills - it might surprise you that a lot of GPs know very little about smoking cessation or breast screening - and I've learned a lot about cancer registers and gold standard palliative care. That's all really good.'* (PCCL)

> *'Technically he's extremely proficient. Where he's gaining is in negotiation and service commissioning.'* (DPH)

The Macmillan Collective Learning Sets: For many PCCLs thrown in at the deep end the Macmillan learning sets offered a lifeline. What follows is a cross-section of views on this aspect of the support programme. It is a commentary on the views expressed by PCCLs and some others.

The CLSs worked extremely well for some people, earning plaudits like these from PCCLs:

> *'I've gone to the most of the collective learning sets … they were really excellent. It was very good to meet regularly with the other PCCLs and our facilitator, who … was just incredibly good at tailoring what we did to what we felt our needs were every step of the way.'*
>
> *'All my training has come from the Macmillan support programme. We've had presentations by individuals with specific skills but most importantly it's a forum to exchange ideas with people who are doing the same as I am. I've found it very useful … It has helped my personal development and improved my presentation and communication skills.'*
>
> *'Total unending support.'*

The thing that people valued the most was the opportunity to meet other PCCLs, to exchange ideas about what to do and how to get things done, to *'have a good old whinge'*. Specific inputs - on commissioning, negotiating, managing conflict or whatever - were very welcome, but the value of mutual support was what stood out.

However, the CLSs did not work for everyone. Attendance fell off in some cases, because people could not manage the time commitment, because they felt they weren't getting much out of it, because they had more immediate support, or because they had taken on too much. An insight into the difficulties some people faced came from an ex-PCCL who commented that the CLS he was in became most effective when the membership settled down: *'the group who stayed together were the ones who were fairly experienced already and the ones who fell by the wayside were people who came into post because the PCT needed someone to do the job'*. The importance of having a group that stuck together and had some momentum was reinforced by various comments.

An unsatisfactory mix of people within CLSs came in for criticism from some respondents. The comment just quoted about people falling by the wayside was seconded by two other PCCLs. The problem was partly to do with mixing people from different Networks, but confidence in the role was the more important factor.

> *'The MSP learning set was wider than our Network, which I have to say I thought was stupid … My impression is that quite a lot of the people from outside our Network weren't doctors and none of them have stayed the course.'*
>
> *'Our learning support group encompassed another Network. The people changed all the time and it seemed to be so hard for them to get any handle at all on what they were supposed to be doing.'*

The fact that the same kind of problem was reported from elsewhere showed that this was not an isolated occurrence. A PCCL from another part of the country told how their learning set was being unsuccessful because *'we were joined with other groups who were not as developed as us'*. In that case the Macmillan facilitator was *'very responsive'* and solved the problem by running two sets in parallel.

Two other views provided very different perspectives on this. A PCCL wondered whether the CLSs should have a mix of people from both secondary and primary care. And a Network Director said that, in their area if not elsewhere, a golden opportunity was lost with a failure to integrate the learning sets with the Network business agenda.

6.4. Summary:

The Macmillan Support Programme was probably of greatest support for PCCLs who did not have access to other management development opportunities. Overall, most PCCLs were keen for the MSP to continue in some form or other. The CLSs worked best where a cohesive group could develop momentum. Where they are working well, there is no fundamental reason why they cannot continue on a self-managing basis where there is continued investment in this mode of clinical leadership. The signs are that there will be continued support for a more focused role in cases where the PCCL is seen to be having an impact, since adequate training and infrastructural support is essential.

7. Case Study Interviews

7.1. Introduction:

The intention of the PCCL initiative was quite straightforward - to fund dedicated time for PCCLs to contribute to the development of Cancer Networks and to help raise the standards of cancer care in their PCG/Ts - and the scheme was relatively modest. It involved a commitment of one clinician for at least one 'session' of 3-4 hours per week. If the initiative were taken up by all PCTs, the total amount of dedicated time would be almost equivalent to one person working full-time in this capacity for each of the 34 Cancer Networks.

This part of the evaluation is based on the telephone interviews and the methods are set out in Section 3 of this Report. The sites were selected to provide a range of experiences from urban to less urban and from having well-developed PCCL schemes to areas where they were less developed. One of the sites (F in Table 23) had a number of Nurse PCCLs. Achieving Research Governance approval for the study was time consuming and was not achieved for two of the selected PCTs (one in each of sites B and E in Table 23). Lack of Research Governance approval meant that it was not possible to approach the PCCLs and Chief Executives in those PCTs affected. However, we were still able to interview the other professionals who were associated with the other PCTs in those Study Sites. Sites E and F in Table 23 each contained a PCT where the PCCL post was vacant. In addition one PCCL in site E refused to be interviewed.

Table 23 sets out the numbers of each group of professionals interviewed at each of the study sites. In total, 78 interviews were undertaken. On analysis of the study findings we found that most responses were generic rather than applying to specific sites only. A decision was therefore made to pool the findings rather than analyse on a site by site basis. The findings are presented as themes, and these are brought together with the Postal Survey findings in the Discussion (Section 8), which looks at the findings in the context of the study Objectives.

Table 23: Numbers of Interviews in each of the Case Study Sites

Site	A	B	C	D	E	F	Total
PCCLs	5	4	5	3	3	3	23
PCT managers	3	3	5	4	5	3	23
Consultants	1	0	2	1	1	1	6
Network directors	1	1	0	1	1	1	5
Hospital Managers	1	1	0	1	1	1	5
User reps	1	1	0	1	1	0	4
GPwSIs	1	1	0	0	1	1	4
GPs	4	0	1	0	2	1	8
Vacant PCCL post	0	0	0	0	1	1	2
Not approved*	0	2	0	0	0	2	4
Refused (PCCL)	0	0	0	0	1	0	1
Total	17	13	13	11	17	14	85

* The PCCL and Chief Executive in the 2 PCTs could not be interviewed.

7.2. How PCCLs came to be appointed:

Following the NHS Cancer Plan, the appointment of PCCLs was underwritten by a joint commitment by the Department of Health and Macmillan Cancer Relief that for three years from April 2001 £5,000 per annum would be given to each PCG/T to fund the post. This was later changed to reflect the mergers that took place as PCGs became PCTs with the amount paid per PCT depending on their population size, with a range from £7000 to £10,000. There was flexibility for PCTs to pool the funds to have a shared PCCL, as long as the number of dedicated sessions was in line with the funding. Guidelines for appointment were issued, along with a description of key roles and responsibilities. It was recognised that some PCOs already had a nominated cancer lead and could use the funds to sustain or augment that investment.

Of the PCCLs interviewed, one third evolved into PCCLs as a continuance of previous work in a broadly similar capacity, while half opted for the role as a specific opportunity. Roughly 10% took it on because no-one else would. Modes of recruitment ranged from informal merging of one role into another or broadening of a particular interest (in palliative care, for instance, or in commissioning), to being invited/persuaded/told to take it on, to being nominated by the PEC, to openly advertised recruitment.

A variety of motives were involved. For one GP who had been working on community palliative care for over a decade it was '*quite natural*' that his role expanded to take on that of PCCL. Another '*had mentioned an interest in cancer … [and] in becoming an appraiser, did a course and decided against that, and was then asked to be the cancer lead without knowing exactly what it was'*. One person had '*long experience of working on commissioning*' and saw it as an opportunity to '*try and make a difference*'. Another '*decided that I wanted to do something a bit more than being just an ordinary PEC member*'; he had no prior interest in cancer but had been involved in commissioning and saw this as an opportunity to continue using the know-how he had gained as PCT Chair. From having always had an interest in cancer and also some experience of commissioning another PCCL spoke of being '*sort of dropped into it*' - but not unhappily: '*Because the cancer agenda seemed to impact on so much in terms of services, I thought it was a good thing to get involved with.*' A GP voiced the sense of purpose that clearly motivated some PCCLs: from early in her career she became

> '*very aware that not everybody was getting the best or the most prompt investigation and treatment, and that always had seemed very wrong … I really liked the NHS Cancer Plan, when we all got that I thought it was great … Cancer is … one of those things that is a crunch time when the health service should be at its best'.*

Nonetheless, she now '*blows hot and cold*' about the PCCL role.

'*A bit of a challenge*' was what one PCCL expected - and it is a phrase that many PCCLs who were interviewed would echo. For some appointees the challenge was too much of a burden, resulting in resignations and recruitment problems that still persist, though to a lesser extent now than initially. This brings us to one of the main issues regarding PCCLs: the nature and feasibility of the remit.

7.3. Views of the PCCL remit:

For anyone not familiar with the Job Description (Appendix 3), a rather hazy impression of the PCCL remit would be drawn from the interviews. This was as much the case among current or ex-PCCLs as among the other respondents. Where the nature of the role, priorities or responsibilities was raised explicitly, only in a few cases were they outlined in terms of the core purposes of the remit. More often, it was sketched in terms of headline activities the role entails or individual respondents' particular interests or current priorities.

In general, the way the remit was described suggested widespread uncertainty about it. Two kinds of interpretation were particularly evident. One was the view that the remit was vague or unwieldy, so it was up to PCCLs to figure out for themselves how to make it workable. The other was an implicit understanding that, in the absence of a consensus as to what PCCLs were meant to be doing, what made their activities coherent was the fact that the PCCL was doing them. Both interpretations tended to regard the remit as being how the role was being performed – essentially the job was what the PCCL made of it.

While some people accepted or welcomed this lack of clarity, it made others uneasy - as will become more evident when we look at views on the feasibility of the remit and PCCL effectiveness. On the other hand, some people did have a clear view of the remit, as in the first two descriptions cited below.

PCCLs' views: The quotations that follow are representative of the ways in which interviewed PCCLs themselves expressed how they understood their remit. The varying shifts of emphasis are worth noting.

> *'My main concerns are taking responsibility for developing primary care cancer services, so looking at the quality of care - palliative care particularly and user involvement - but also liaising with the hospital sector and liaising with the Network.'*
>
> *'My responsibilities are to provide a care perspective for cancer within the PCT, to ensure that we have good representation of primary care issues relating to cancer within the primary and secondary care interface … [and other] responsibilities that reach across clinical governance, across delivery of services, and across commissioning.'*
>
> *'Communicating with the practices in the PCT on cancer matters. I also attend county and Network meetings looking at the strategic development of cancer care. I'm also involved in developing primary care cancer standards, and communicating with PCT management about clinical cancer care.'*
>
> *'Basically sort of representing the PCT at our various commissioning meetings … Also being involved a bit in the Network - with various projects there. I've got involved in the*

> *National Primary Care Standards Database Group … Oh yes, and monitoring our two-week wait data.'*
>
> *'I had the Macmillan job description, which I have to say I did not find particularly helpful. So really what I tended to do was build up my own work programme as much as anything else, which was probably more reactive than proactive but seems to fulfil most of the expectations that others seem to have of me.'*
>
> *'The job description is long and in areas vague. By mutual consent with the other PCCLs and the Network I attend the skin tumour board, and the head and neck tumour board meetings. I also sit on the head and neck implementation board and the IT board.'*
>
> *'I sit on the Cancer Network Board and liaise between the board and the PCT. I sit on various sub groups of that board, the diagnostics group, the primary care prevention board and the upper gastric intestinal tumour board and I have to work within those groups to give the primary care perspective. I also have set up a cancer liaison group within the PCT, to make it focus more on cancer as a priority. I liaise with GPs, and I'm gradually working my way around the different people locally who are to do with cancer … I've developed a special interest in access to endoscopy which I feel is a very neglected area …That's just some of it.'*
>
> *'Currently I'm involved in the two-week wait, representing the PCT at meetings with various stakeholders and reporting back to the PCT. Advising the PCT on the cancer data sets, and also advising on day-to-day things like any problems with the local hospital and progress in regard to the two-week wait. [I'm also] getting involved in palliative work. It's quite broad.'*
>
> *'Predominantly acting as the central conduit of cancer-related information between and within the PCT - between the clinicians, commissioning and management … Most cancer-related matters come to me.'*
>
> *'Well, the job description is pretty lengthy but at the moment essentially it's about monitoring referrals, breaches and targets … Then there are those things that we are trying to develop … under the gold standards framework facilitation. Then there are the inevitable reports and plans and things that I get involved with and going to various other meetings, Authority-type meetings.'*

Different understandings of the role were apparent, irrespective of whether PCCLs were in the same or different Cancer Networks, and regardless of whether the post was held by a GP or Nurse. All of the quotes above were from PCCLs who were GPs. The two below are from ones who were Nurses, both within the same network. Again, the differences in emphasis are interesting.

> *'My understanding is that I'm the link between the Cancer Network and the PCT, so I would take the lead in any initiatives that come out of the Network that affect primary*

> *care. I think, well I know I do influence the commissioning process. I work closely with the commissioning team to put a clinical slant on that. And I would say that [for the PCT as a whole] I'm there as a resource really in relation to the clinical element of cancer issues.'*
>
> *'Crickey! Well I'm responsible for giving the PCT a strategic direction on the way forward with cancer care. We don't commission; we have another PCT that commissions on our behalf but we meet with him on a regular basis [to put forward] our views on that and have some input into commissioning arrangements with our Acute colleagues. I chair a local cancer sub-group which we have developed … liaising with the GPs to identify what their needs are as regards training and information and trying to [gain acceptance for] our action plan. Also working with our Director of Public Health [to see] how we can improve services locally for patients with chronic care needs.'*

Other views of the remit: Among the Directors of Public Health, Chief Executives and other senior managers to whom we spoke, 'clinical leadership', implementing the NHS Cancer Plan and acting as a channel of communication with the Cancer Network were the dominant themes in how they described the PCCL's role:

> *'Firstly, being the champion, the advocate, the ambassador for cancer and its importance across primary care, both at practice level and corporate level within the PCT … Secondly to represent the PCT and primary care in general on the Cancer Network.'* (Chief Executive)
>
> *'first and foremost to support primary care clinicians, not just doctors but nurses and other clinical staff, in improving prevention, diagnosis and treatment of cancer.'* (DPH and Board lead on cancer)
>
> *'working with us to identify priorities for implementing the NHS Cancer Plan locally and providing the clinical leadership in their implementation.'* (DPH)
>
> *'I think [it has to work at] a number of levels really, but something about just raising awareness of the cancer agenda, so that people at all levels in the PCT understand what the NHS Cancer Plan is saying and getting some sort of ownership at all levels. It's also about building really good relationships with colleagues in our local hospitals, so when there are issues … things can be sorted out a lot easier than perhaps they have been in the past … To be sort of the main co-ordinator of cancer activity really.'* (DPH)
>
> *'to be our main point of contact with the Cancer Network, to advise and inform us about what's happening with the Cancer Plan and tell us what we need to do to make the Cancer Plan work'* (DPH)

While such general views would gain wide agreement, it was striking that, among senior colleagues with whom PCCLs were working closely, there was no consensus about the 'strategic' aspect of the remit, set out in the first line of the job description. One DPH summed up the role as follows: '*local implementation of national policy, local interpretation of national policy, and local development of policy where it doesn't exist nationally, and determining the commissioning priorities for cancer*'. A broadly similar view was expressed by a senior commissioning manager who regretted that their PCCL was '*just not active enough*' held that the PCCL '*should be influencing the strategy and leading development planning*'. A contrary view was held by a Director of Commissioning who believed that palliative care should be the main focus of the PCCL's role, which he saw in terms of '*a sort of leadership, strategic leadership, looking at pathways and that*'; but maintained that, while it was helpful to have the PCCL involved in planning palliative care, strategic planning in relation to it was his own remit, not the PCCL's. A Public Health Director thought that not only did strategic decision-making processes bypass the PCCL but also doubted whether GPs - being '*very clinically focused, which is what we want from them*' - were capable of strategic thinking since '*the largest population they can grapple with is the practice population*'. The Network Directors we spoke to also tended to put the emphasis on improving clinical practice and systems. As one of them put it, '*I think, by definition, the PCCL role is not about a direct impact on patient care, it's about putting systems in place to ensure others can have a direct impact on patient care.*' Another Network Director argued that, whatever the job description might say, the PCCLs' main objective should be '*clinical, that is working with colleagues to improve their index of suspicion and speed of referral*' - with elements such as commissioning of palliative care being important but less significant in terms of systemic impact. Other Network Directors regarded the primary-secondary interface as the prime focus of PCCL intervention.

Crux of the matter? The range of views cited were not isolated differences of opinion, but were competing arguments that affected how the role was perceived. The crux of the matter seemed to be this. As some saw it, overall strategy had been set out in the NHS Cancer Plan with commissioning decisions being taken by PCTs, and PCCLs should, therefore, focus their efforts on improving clinical practice and liaison with secondary care. A second group favoured a re-distribution of cancer-care resources to take account of the fact that, notwithstanding the importance of hospital treatment, cancer care happens mostly in primary care settings - and PCTs are responsible for preventative strategies. This group saw PCCLs as being at the forefront of such a re-alignment of priorities, and therefore they wanted PCCLs to have more say with regard to commissioning. But most of the Oncologists interviewed thought that PCCLs had more influence on funding decisions than most PCCL saw themselves as having. A third group stood at the intersection of those views, tending to frame strategy - and the PCCL role - in terms of the interface between primary and secondary care.

These views interact with another factor mentioned earlier. When looking at how PCCLs' view their remit, it was noted that most of them described it in terms of activities rather than overall purposes, in common with most people when asked about their role and responsibilities. It is a general feature of organisations that most people have only hazy notions of what their work is for; they tend to rely more on describing the activities it entails. For most GPs there was the added factor that their contractual relationship to the NHS is based upon a fragmentary approach to defining their responsibilities. So, for the majority of PCCLs who were GPs, the PCCL remit was overlaid upon a mosaical base - made yet more prismatic by the complicated relationships between primary, secondary and tertiary care sectors. It is easy, therefore, to form the notion of the PCCL remit as being rather perplexing and boundless - especially given the manifold implications of cancer. Whether or not they were perplexed, most of the people interviewed had concerns about the feasibility of the remit.

7.4. Feasibility of the remit:

The prime issues concerning the remit's feasibility were summed up by a Chief Executive who said:

> *'I think it's an incredibly difficult role to do … It's not very clear what you are supposed to deliver … It is particularly difficult if you are not a member of the PEC because you are not sufficiently privy to what goes on within the Trust to know what line to take on things …*
> *What they end up doing is going to a lot of meetings because Cancer Networks have hundreds of meetings. Whether they have much influence at these meetings I think is debatable.'*

She also voiced concern that some key figures in the Network expected PCCLs to be *'fully genned up on everything to do with the PCT and cancer, and will be able to speak authoritatively'* - which would be ideal but was not realistic, and she would prefer the PCCL to concentrate on improving the quality of care in general practice *'and actually making sure we have got in place the things we need to have in place.'* She went on to question some of the assumptions underpinning the PCCL scheme and various other initiatives:

> *'We have to make our minds up whether we want GPs to develop managerial skills and spend their time being managers or whether we actually want to use them for what they are good at, which is being doctors. Get the expertise and the clinical direction from them, and not force them to do stuff which most of them find deeply tedious or difficult, baffling and frustrating …'*
>
> *'The new orthodoxy is that clinicians want to get involved in managing change. I don't think we have overwhelming evidence for that. They are certainly very keen on influencing direction - but actually managing the implementation?'*

We will leave that question hanging while we look at how others viewed the feasibility of the PCCL remit. The clarity of the remit has already been called into question. One PCCL spoke for others who were exasperated by it:

> *'I don't think they [Macmillan Cancer Relief] ever knew and I don't think the government know, or any of us who have done the role know, what we are supposed to achieve in these three years.'*

On the other hand, some were attracted to the role because they saw it quite well defined. The balance of opinion was that the brief was not as clear as it should be, and that it needed to be more tightly focused. A Director of Commissioning suggested taking this to the point of having specific, agreed objectives, *'so that it can be performance managed as an integral part of the PCT's performance management and objectives'*.

Sharpening the focus, and embedding the role: The notion of performance managing the role is likely to cause concern while many PCCLs felt they were being expected to do more than the time allowed or other resources permitted. Yet the idea of integrating it more with 'mainstream' PCT management would be seen as a step forward. Drawing together several strands of opinion, the most welcome changes would be a sharpening of the focus of the remit combined with bedding it into a managerial and support infrastructure. Among other things, sharpening the focus would help to resolve the problem of overlaps between the PCCL remit and others. As one PCCL put it:

> *'I am not keen to do a job for which I take money unless I am doing it properly. On the other hand the job description is so wide and there are so many other people doing some of things that we are supposed to be doing in one session a week, that it is very, very hard to select what to do.'*

Much of the confusion stemmed from a blurring of the lines between clinical and managerial roles. The Director of Commissioning quoted above argued that the five 'key roles' set out in the Job Description:

> *'are really corporate responsibilities of the PCT and the individual role of the PCCLs should focus on clinical practice and improving clinical behaviour rather than on management issues like baseline assessment information and commissioning. They clearly are clinical leads and they should be leading improvements in clinical care.'*

The further need to embed the role within a leadership infrastructure was stressed by the Chief Executive (not the one cited at the top of this section) of a PCT where the PCCL was supported by a dedicated manager, whose post was funded jointly by the PCT and Acute Trust. The aim was to strike a balance between clinical leadership and implementing improvements, and thus realise the collaborative potential of the role. He explained the reasoning thus:

> *[Given the collaborative nature of the PCCLs' collaborative remit] 'you can either say, look, what we want is someone whose job it is to handle the thing in a kind of technical process way, or you can do what we've done which is to say, actually there's a really important leadership role here, but exercising the leadership role isn't the whole story. There has to be some operationalising of plans and ideas and strategies. That takes a huge amount of time and energy and effort that frankly neither … nor anybody else at that level would be able to commit, and nor frankly is it necessarily the best use of their time. So what we've tried to do is to get a balance between senior clinical leadership and somebody that devotes their time to making things work. The roles are complementary and I've no doubt in my mind that if we didn't have that [synergy] we'd have to re-invent it in some way, shape or form.'*

That kind of approach could be taken only where cancer was regarded as being of sufficient priority, but that could not be taken for granted. It was evident that some PCTs regarded the PCCL initiative as marginal to their clinical priorities (heart disease, diabetes etc); one Chief Executive called it an imposition. Voicing this concern, a Director of Public Health also highlighted tensions within the field of cancer care because *'an awful lot of the money that the PCT has for cancer services goes to cancer centres and [implementing] NICE guidance about secondary and tertiary care'*, with the result that *'not much is left actually for primary care cancer services'*. The Director of the Network to which this PCT belonged regarded such views as mistaken and short-termist - which gave an insight into the politics with which some PCCLs had to cope.

'Being on the PEC': There was widespread agreement that being in the decision-making 'loop' was crucial to the remit's feasibility. It boiled down to having some 'clout'. The postal survey highlighted the importance of having good links with the Network, Commissioning Managers, Acute Trust Clinicians and the PEC - in that order. In the interviews, membership of the PEC or Trust Board - or other senior management group - was one of the main concerns. As one Network Director put it, such membership was *'vital'*. PCCLs who did not have those links saw themselves, and were seen to be, at a clear disadvantage when it came to knowing about or influencing decisions and general policy:

> *'I think to do my cancer lead job without being on the PEC or some other senior management role would make it very, very difficult to be effective. Others are medical directors but they are then part of the system. If you're just a little GP not in the system you would be very much on the sidelines.'* (PCCL)

> *'I don't think I've done it that well, to be honest, because of the fact that I'm not on the PEC'* (PCCL)

However, being on the PEC or equivalent also had its problems; one ex-PCCL resigned because he felt that lip service was being paid to his role, but said that the underlying reason he was *'peripheral to decision-making'* was because he couldn't afford to take any more time from his practice.

Against the general trend of opinion, some PCCLs were content not to be on the PEC/Board, but they tended to be former members who were also confident of their ability to network effectively and exercise influence. The strength of such links - i.e. the quality of the relationships - seemed to matter more than the fact of having them by virtue of a former position. One DPH regretted their PCCL's lack of influence notwithstanding having been on the Board. And at least one of the PCCLs interviewed had fallen foul of what appeared to be some 'fancy footwork'. A Board member when the PCCL scheme was introduced, this individual was persuaded by his fellow-directors to take on the role because of a known interest in palliative care. He then relinquished his directorship to concentrate on the PCCL remit, but now was close to giving it up because he felt completely sidelined.

One of the points made by the Chief Executive quoted at the top of this section was that PCCLs could be subject to unrealistic expectations in Cancer Networks. That was the experience of some of the PCCLs in the Network to which her PCT belonged. A few of them linked together to help each other get a grip on the remit - which apparently caused some anxiety in other quarters on account of assumptions that they all had a lot of say over commissioning. In fact *'some of us had more authority than others and some had more understanding than others … but we were all being painted with the same brush - they all know what they're doing - but some of us didn't'*.

Overall, there was some ambivalence about Cancer Networks among PCCLs and their PCT colleagues. On the one hand there was the influence Networks exerted over the allocation of cancer care funding, and on the other hand was the obligation on PCCLs to attend Network meetings and the expectation that they would actively contribute to the Network's development. Opinion was divided about Network participation. Some PCCLs regarded it as well worthwhile, and probably were correspondingly active in their Networks. Others regarded it as a time-consuming and rather pointless burden. The key factors seemed to be how sure of themselves and how well supported the PCCLs were, and the dynamics and efficacy of their particular Network. We will turn now to look at the issue of support vis-à-vis the pressures on PCCLs' time, and come back to Networks when looking at factors helping or hindering PCCL effectiveness.

Time pressures: We have already touched on the fact that some PCCLs felt they were being pulled in all directions and had too much to do in the time available, particularly if they were trying to combine the role with full-time general practice. As one PCCL put it, *'with all the paperwork and meetings, it's just not do-able in the time they give you'*. In sharp contrast, a Cancer Services Manager found it hard to believe that their PCCL *'is dedicating that amount of time to it and still not turning up to our quarterly meetings'*. Another PCCL said *'I'm actually providing a lot of input that is completely un-resourced, so the people that pay for that emotionally are myself and my children'*. Concerned about the disheartening effect on their morale, a Network Director commented that *'the scope of the job is ridiculous for one session a week. Without the support they can't possibly do it, so they just sink under it and give up'*. Another Network Director saw some PCCLs feeling overwhelmed by the role, *'and we said, well, you've got to decide where you're going to focus … but, to be fair, every manager has to face that problem'*.

Much as some PCCLs felt unduly pressurised, others would go along with the tone of that last comment. Some resigned themselves to a low-key approach: *'I know that I don't put enough time into it to make a good job of it but I do what I can in the time I've got'*. A city-based PCCL who was a GP thought that time was not the issue; in his view, one session a week was *'plenty provided that it is channelled in the proper direction'* - and that meant not taking on tasks where *'there are managers being paid by the PCT to do those jobs'*. A DPH who had been doubling as a PCCL (because they couldn't recruit one) thought that:

> *'Being the Cancer Lead doesn't mean to say that you are personally responsible for delivering every Cancer Plan target. It does mean that you are a champion … someone who can understand the issues and can highlight them when they need to be highlighted - and that's a big enough job in itself.'*

Time was not the issue either for another DPH who said that what the PCCL needed was *'more support - managerial support really'* - and then confessed that their own situation in this regard was *'pretty ropey, to be honest.'*

When raised in the context of time pressures, GPs tended to relate the issue of support to administrative back-up, and to have more concerns about that than Nurse PCCLs, who, as a Network Director put it, *'have tended just to get on with it, whereas GPs tend to look for admin support'*. A more crucial issue was whether there were supportive infrastructures for clinical leadership.

The need for support: *'You can't just appoint someone as a PCCL and then sort of let them loose, because we all have our particular interests and theories'* was how one Chief Executive began to explain how she saw her own role in supporting their PCCL. For her it meant helping them to understand organisational and policy issues, and working with the PCCL to *'get into a position of power, where they actually influence policy'*. Many PCCLs would welcome such direct support, yet on its own it would not be enough. A PCCL described the learning curve:

> *'I think, if I was honest, I expected to be incorporated more into things like the clinical governance side of the PCT, but somehow the clinical governance leads haven't really thought cancer has anything to do with them. My main link has been with commissioning whereas it should have really been with clinical governance. I think the Trust are recognising now that the Clinical Lead should be very much integral to the PCT.'*

It was, however, going to be an uphill effort, according to that PCCL's Network Director:

> *'the problem is support and status … A lot of PCTs do not understand clinical leadership in the context of primary care, and most GPs don't understand clinical leadership, so it is going to be quite a long haul….'*
>
> *'If this is to be real then I think the clinical leadership role is a day a week, and they need at least half time middle management support from within the PCT and significant leverage in terms of where resources go. I think those are the minimum requirements, to be honest. Less than that and they will quickly become a cypher, someone who sits round a table but has no power.'*

This brings us back to the need to create supportive infrastructures for clinical leadership. It also underscores the need to *'consolidate'* the role, as an ex-PCCL put it, making the remit more sharply focused, distinguishing it from others (e.g. Palliative Care Facilitators) where there were synergies but also confusing overlaps, and attaching specific managerial support to it. That ex-PCCL also recommended freeing PCCLs from attending so many meetings. Other developments pointed towards this too. As a serving PCCL pointed out, the introduction of standards for cancer and palliative care should make it *'more straightforward for a cancer lead to literally lead on those areas, which I think is more appropriate than trying to take on the world and its dog all in one go'*. Moreover, *'once there are standards and things PCTs can be judged on, the importance and sense of having an appropriately resourced and managed system [supporting] will become all the more necessary.'*

Streamlining the role and giving it real 'clout' was also likely to facilitate more focused collaboration between the primary and acute sectors. One of the Oncologists interviewed argued that, rather than taking on too much, it would be much more productive if the sectors were to focus their joint efforts on *'one or two clearly defined projects they are going to achieve year on year, making it clear that's their flagship, that's the thing that they will do this year - and then making it seen to be done.'*

Despite the drawbacks of the remit as it stands, it has to be borne in mind that the PCCL scheme has been a great success in some places. One Network Director would not even change the role: *'Ours have been brilliant and I just dread to think what's going to happen with all this talk about funding and also the new GP contract. I dread to think how we're going to manage if we* *don't have them.'* On that note we turn now to look at how the people interviewed assessed the impact of PCCLs.

The impact of PCCLs: An analysis of how PCCLs rated the impact they had is featured in the findings of the postal survey along with a commentary on their achievements, factors contributing to such achievements, and limiting factors or barriers - as perceived by PCCLs' and by PCT managers. The key points are borne out in more depth by the case study interviews. However, it will be more useful here to trace the interplay of factors affecting the impact of PCCLs, and to throw more light on the implications of trying to make a success of an uncertain remit in a context of organisational flux and competition for resources.

Most of the current or former PCCLs interviewed regarded themselves as having had some significant impact. Those that had doubts represented a sizeable minority - in the region of a quarter to one-third. Opinion was similarly mixed among the other people to whom we spoke.

Some of the most favourable endorsements came from non-PCCLs. The view of this DPH, commenting upon a job-shared PCCL, summed up the kind of impact PCCLs were typically seen to have:

> *' I think they've been very good at bringing cancer into its rightful position within the PCT. The other thing they've done is to make that link between the Network and the PCT. They've made cancer a reality for us as opposed to something that somebody else does.'*

One of the most positive endorsements came from a Chief Executive who was full of praise for how their PCCL dealt with the complexities of the role:

> *'I think she has got a clear grip of the agenda … She understands the issues, she takes constructive action, she influences where necessary, she keeps the cancer on the agenda, and I think in terms of clinician involvement it has worked really well. There is a lesson in there about why it has worked really well and what can we do in other areas, whether its diabetes or older people … something about roles and responsibilities and being clear about the nature of the intervention, and having the time to do it … And she is really clear about the limits of the role too, so she is clear that she is not doing commissioning, but there is an important linkage to be made to ensure that we spend the money on the right*

> *things. She is quite politically astute and understands that you don't win all the arguments all the time.'*

Interestingly, the PCCL concerned was not on the PEC, and she referred to her impact on service improvements in very modest terms, mentioning the two-week waits and a PCT wide educational programme to raise understanding of cancer. Another PCCL described his achievements in these terms:

> *'I've been able to make them prioritise cancer more, to accept they've got a commitment to Network, not seeing themselves in isolation - a commitment to build bridges and improve relations between different providers. Two of our local providers had not been able to talk to each other until I got them across the table. I've been able to highlight the endoscopy shortage and [win support for] extra resources are going in … There's been a lot on a smaller scale as well - for instance, the cancer newsletter to the GPs, highlighting best practice and pointing out where things aren't working out … There's a range of things.'*

To draw attention to inequalities, he explained how he *'gave a talk to the board and produced a table of waiting times for endoscopies and colonoscopies, and when I stopped to let them look at this particular slide you could hear all their jaws dropping.'*

Among PCCLs who felt they were not making much of an impact, common themes were that they had to spread themselves too thinly because the remit was too broad, that lack of support had made the task impossible, that lip service was being paid to them and cancer was not a priority for PCTs. There was also frustration at endless meetings where *'We all know what the agenda is and we keep talking about how to deliver it … talking about the same thing over and over again.'*

Some Cancer Services Managers were unable to understand what PCCLs were doing. A GP with a Special Interest in cancer was unenthusiastic about the impact they were having:

> *'They certainly helped push through the two-week waits for referrals from GP to hospital. Apart from facilitating the two-week wait locally I am not sure, I really couldn't say. Nothing springs to mind … [The role] either needs to be re-vamped or got rid of.'*

This ties in with comments by some GPs and others along the lines that *'cancer certainly is higher up the GPs' agenda now'* and they saw improvements in referral processes and care pathways, but that *'exactly what role [the PCCL] plays in that I'm not sure, to be honest … A lot of those developments are national.'* One of the PCCLs put this in slightly different terms: *'a lot of what is going on is just us trying to adapt Government guidelines to local conditions really.'*

An important factor is whether individual PCCLs saw themselves contributing pro-actively to developments in cancer care. However, any interpretation of their impact was complicated by the fact that PCTs had little control over their own policy and actions in this respect, most of which was determined by Cancer Networks. This was why some PCCLs regarded the Network as their prime sphere of influence, and also why some people were more inclined to attribute improvements in cancer care to national policy and well-functioning Networks than to PCCLs. There was also the point that, for there to be noticeable improvements in the primary-secondary interface, there had to be favourable factors on the acute side as well as the primary. The discussion that follows draws mostly on the views of non-PCCLs to illustrate how these factors interacted and impinged on notions of what PCCLs could achieve.

Influence on strategy: Asked whether their PCCL was having any influence on overall strategy, a Chief Executive cited interventions he felt were significant, yet wasn't sure that having a designated post was a prerequisite:

> *'I think that's an interesting question … I don't think I could genuinely … be absolutely certain that - if we didn't have this designated post - we wouldn't have done a, b, c, d, and e. But there are things that have been done - like making sure that the voice of and the perspectives of primary care are properly taken account of in the Network. That's an example of something that simply was not happening. Our Network was being dominated more and more by kind of pseudo-tertiary issues without real consideration of the whole cancer care pathway and the part that other practitioners have to play. So maybe that's another achievement that I should have picked out earlier on. And there are things like ensuring there was a dialogue between the clinicians when the local hospital was failing to meet the two-week wait target. Instinctively I know that having somebody with authority to implement that made a difference. But I guess the truth is, maybe we'd have addressed those issues in a different way if the post didn't exist.'*

The Chief Executive whose praise of their PCCL was quoted above thought that she had no direct influence on PCT strategy (and not because the PCCL was not on the PEC or Board) but saw her having more influence on it through the part she played in the Cancer Network - *'by making sure that primary care is seen as an equal partner in setting priorities across the*

Network.' It was one of the oddities of the situation that, by influencing thinking at Network level, PCCLs could exert more influence on cancer policy and objectives from outside their PCTs than from within - if they were able to do so individually or acting in concert.

Yet PCCLs could still feel frustrated by having only marginal influence on decision-making, because it was hard to link cancer strategy to actual budgets, and PCTs' hands were tied a lot of the time. Referring to the cancer boards that constituted another forum for raising standards, one PCCL described it thus:

> *'So the boards are trying to establish excellence and equity of treatment … but the powers-that-be in charge of PCTs haven't got enough power themselves because the government has restricted their movement so much, and all the new monies are tied up under various different labels so they're quite difficult to find. So it's very hard to change anything [because, in effect] we haven't got access to a cancer budget … [and] in our particular area the money for [developing cancer services] has all been taken up by debts at the local hospital. There isn't much prospect of change, so we have to work on the bits that we can influence really.'*

Apart from work on the ground, he had focused his efforts on trying to make sure that PCTs were collecting the data needed to pin down the reasons for wide variations in access to cancer services. This was another uphill battle, he thought, because *'There seems to be a bit of collusion between the SHAs and the PCTs: they are not actually collecting the data to monitor the targets, which aren't strictly requirements, they're only suggestive targets.'*

This brings in the point that cancer was not a priority for PCTs, nor does it count for much in the new GMS contract.

> *'Cancer is such a small part of general practice and primary care. You only need to look at the new contract: cancer hardly features on it and therefore a lot of GPs aren't especially interested in it and it's not seen as a big topic in primary care … and I think that's where having a PCCL is important, because it pushes it up the agenda.'*(PCCL)
>
> *'Within primary care generally, cancer is something that a lot of the GPs don't see as a priority … Your average GP will see only eight new cancers a year.'* (Network Director)

Yet, as a Director of Commissioning noted, *'10% of our acute commissioning budget is cancer-related. It's big money.'* Another factor was that the basic targets for cancer care had more direct implications for the acute sector than the primary:

> *'Most of the initial targets you had to meet were secondary care targets. Primary care targets tend to be around CHD and diabetes and … getting registers going and all that sort of thing. So that receives a lot of input, whereas most of the cancer targets were for hospitals to meet, not for the GPs.'* (PCCL).

This highlights the point that whatever part PCCLs and their colleagues have played in meeting those targets, success depended mostly on action in the acute sector. A Consultant Oncologist brought the two aspects together, so his views are worth quoting at length, starting with his appreciation of the PCCLs' role in facilitating the two-week referrals.

> *'… the primary care leads were very good facilitators in trying to improve that. Now it's up and running and people are just taking it as read really. We had a slow start with that and for our breast cancer services we were bottom of the league. But we've improved our act considerably so now we are meeting that target very well. We still have breaches in that patients are still not being referred or inappropriately referred, and I don't see how the system can move on any further. There will be good GPs that know how to use the system to the advantage of their patients and there will still be GPs that are behind the times and struggling.'*
>
> [Asked about PCCL impact] *'Probably less than the contribution made by secondary care getting their act together. I think the main thing that changed things was monitoring what was being done and feeding back those measures, and making hospital consultants realize that they were being judged along with their peers. It came through peer pressure - they didn't want to be bottom of the list. And I think that was more important than any of the initiatives within primary care at a time when primary care was being re-organised and many GPs had other more pressing things on their minds.'*

While recognising the contribution PCCLs can make, this interviewee regarded them as an unaffordable luxury:

> *'I suppose I feel that it was a luxury to have these people involved. They were certainly valuable, and the particular person who had the post to start with was an excellent communicator, a very good advocate, and a very good facilitator, and we made progress faster than we would have done if she hadn't been in post. But on the other hand, I still view it as a luxury. It doesn't come cheap. And when I see the other things that are still wrong with cancer services which are not properly funded, it makes you question whether you get value for money … In an ideal world it's a valuable post but in the current economic climate it's a luxury we can't afford.'*

This Oncologist would put more trust in patient empowerment:

> *'I'm a great believer in patient empowerment and I think initiatives like the patient- held records are the way forward … I think the process of trying to educate GPs has failed. We are now in the world of trying to educate the patient to educate the GP. And I think that's the way that I would be trying to move things forward, to empower the patient, to improve the direct access link from patient to hospital, bypassing the GP in many situations … I'm not in any way trying to play down the role of general practitioners. It's fundamental and I constantly say to my patients that they really only have one proper doctor and that's their GP … The continuity of care must remain with the GP. But I don't think we in the hospital service can engage with every GP, and the avenue to that engagement, facilitation, must be through the patient.'*

This brings us back to PCCLs' educational role vis-à-vis their own colleagues. While most interviewees would not expect PCCLs to have any direct impact on patient care, their part in raising awareness of cancer issues and best practice was a crucial element of the overall strategy to improve the primary-secondary interface and develop more integrated services. It appeared that the majority of PCCLs were most at home with that role, and it was in line with many other people's expectations. This, presumably, accounted for the tendency of PCCLs to narrow their sphere of activities to palliative care, regarded by many as having been too long ignored, yet the degree to which Network Directors and DPHs reinforced that narrowing of approach must also be salient. However, the strong disposition to home in on practical issues could have only limited impact unless it was matched by appreciation of the need for integrated planning at various levels as the prerequisite of integrated service delivery. As a Cancer Services Manager pointed out, PCTs had to take the initiative on this and it should be the PCCLs' prime objective:

> *'Integration at the planning level: having the clear vision about how they should integrate together and having the involvement to enable that to happen in practice. Because the PCTs are the commissioning organisation it's their responsibility to do that. As providers, we can try and push that forward but the main thrust needs to come from the commissioners.'*

Among other things, in her view, this would begin to remedy imbalances in expertise and other resources, the amount of expertise located in secondary care being *'completely out of balance with what primary care is putting into the agenda.'* As things stood, those imbalances made for what one DPH called *'an unequal game'* between primary and secondary care which PCCLs alone could not hope to remedy.

It would be foolhardy, nonetheless, to discount a problem many PCCLs faced: trying to have strategic impact where there was no organisational strategy worthy of the name. In the view of one Network Director, while there were exceptions, *'most PCTs don't have a strategy for anythin.*' This was not just because they are still finding their feet. It was also a matter of organisational capacity:

> *'There are some PCTs - mostly though not exclusively those that existed from 2000/01 - who are doing the things that only primary care organisations can do very well, and are doing the things that health authorities used to do ever better, but they are few and far between. They tend to be the smaller ones actually, because bigger PCTs are really small health authorities. Too small to do the health authority stuff and the corporate stuff competently, but too big to be flexible and effective commissioners. If you look at [this Network area], [XY] is a very small PCT which is an astonishingly good commissioner and has managed to do the corporate things competently as well, mainly by taking good people from the health authority. But if you look elsewhere, [this city] or [that city], you find really poorly developed PCTs having not as much impact as the previous health authority had, but not doing the local commissioning stuff or the clinical development stuff well either. They're failing and they're typical of most PCTs, and 'Shifting the Balance of Power' hasn't shifted power at all, it has shifted the responsibility for failure.*' (Network Director)

Clearly, organisational capacity can be a problem for PCTs. It came through from a number of interviewees that some PCTs were inclined to discount cancer as a major health threat because at present, thanks to demographics, they had far fewer cases than average. As the Network Director just quoted observed, *'if they had any sort of public health leadership they would be recognising cancer as a major threat to their community [in years to come] and not something that is someone else's problem.*' Other PCTs already had high rates of death from cancer yet still could not come to grips with it being a priority. *'They can whitter and whinge about smoking cessation and diet but their population are still going to die of cancer. The only difference will be the age at which they die of cancer.'* Pressure to 'feed the beast', as the saying goes, can undermine genuine initiatives and sap people's commitment to change.

'Early days yet': Notwithstanding the issues outlined, most of the people interviewed wanted the PCCL role to be more sharply focused and developed rather than discontinued. One of the Oncologists was highly critical of the variable quality of PCCLs, but said that *'for them suddenly to go would be an absolute tragedy.*' In so far as there was any consensus, it was that it was *'early days yet'* and the initiative needs to take hold.

> *'The Network has been up and running for seven years and it's only in the last two or three that they have really had an impact, so we can't expected PCCLs to have had a huge impact yet … It's early days, though if we're being serious about the primary care role then they have got to empower PCCLs and to fairly tolerant of the slow take off.'* (Network Director)

> *'Definitely within the Trust that I work in people are listening more, and with the Cancer Plan as well it's certainly more of a priority.'* (GP)

> *'I think it should continue. Anything new takes a while to bed down and to change it now and do something completely different would be a disaster. Maybe in five years time we can re-think the model, but for the time being it should definitely continue … However, they need to have a lot of support because there are major challenges in doing this.'*(Oncologist)

> *'We need to give it more time. It's unlikely you're going to find [evidence of significant] direct benefits at this stage, but I don't think that we should dump it because of that. I think it's the right way forward. We've got to concentrate on the team, the PCT Primary Care Team. I think that for the future we need to look at developing nurses or allied health professionals in primary care who are key workers for patients suffering from cancer. At the moment specialist nurses only cover the secondary care side of a patient's cancer journey, and they only come on board at the point the patient's diagnosed, and the post-diagnostic process can be very stressful and difficult for the patient. I think that if we could develop the Nurse Specialist role in primary care, that would actually really boost the PCCL's role.'* (Network Director)

If the initiative was to take hold in whatever form, it would matter a lot whether current and former PCCLs felt a sense of job satisfaction. We will come back later to views of how the role might be altered.

Job satisfaction: The impact of the remit has already been discussed, along with the crucial factor of managerial support. So here we will simply let a range of comments give the flavour of views on the question of job satisfaction.

> *'Anyone who looks into the job seriously will quickly come to realise that the task is impossible, the time allocated is ridiculous and the support inadequate so why would they want to take it on.'* (Network Director)

> *'I had no idea what to expect because I've done nothing in my whole career apart from seeing patients, as a totally full-time GP. This is the first time I've attended meetings [of this kind]. It's a completely new experience. It's very nice networking with people and listening to others' views on various things. It's easy to be isolated in general practice … I think given the fact that [I've only been doing it a year], I think I have actually achieved quite a lot.'* (PCCL)

> *'I thoroughly enjoyed it. I passed it on a couple of months ago but I'm missing it already.'* (ex-PCCL)
>
> *'I would have been better off just being a GP and having a quiet life, rather than trying to fit this in and trying to juggle meetings with surgeries and the out-of-hours meetings. So, I feel positive that I have made a contribution, and I'm fairly pig-headed in that I don't like to let go until I have done what I wanted to do. But, I'd have been better off not doing it, certainly.'*(PCCL)
>
> *'I think the more you put in, the more satisfaction you get out of it and, as I say, it's grassroots so that's very satisfying. It has been very interesting going and talking to colleagues at the hospital and seeing the big picture as it were. That's been extremely useful and I've sort of changed my mind about an awful lot of things that are going on … As a model I think it has been excellent … much more powerful than I would have thought at first.'*(PCCL)

Pressure to attend numerous meetings was one of the most frequently mentioned bugbears, along with what was regarded as pointless bureaucracy, particularly irritating for those with little or no administrative support. The Macmillan Baseline Assessment was considered to place unrealistic demands upon PCCLs in PCTs with a lot of practices; that it was *'farcical'* to expect all GPs to fill it out, and even if they did, it would not accurately reflect what they were doing; and that nothing came of it - PCCLs got no feedback despite all the effort. It is not clear whether this affected uptake of the MSP. Training and development issues are examined in Section 6 of this Report.

7.5. Contribution to Networks:

The PCCLs' role in relation to Cancer Networks is twofold: to bring PCT views and concerns to bear on the development of cancer services in line with the Cancer Plan, and to serve as a channel of communication between Networks and PCTs. In addition to each Network there are also various tumour groups and other cancer groups with a variety of names. There were, therefore, several layers of interaction between various interests, and pressure to attend lots of meetings, but the decision-making processes seemed to be far from transparent. PCCLs were in the middle of all this, trying to fulfil an uncertain remit within a system that very few people understood.

While the Postal Survey suggests quite a high level of involvement in Networks, the interviews indicated that it was more patchy. From what PCCLs and others said, only a minority of PCCLs were active in Networks and finding it worthwhile. Again, the '*early* *days*' factor has to be taken into account. To add to the confusion, as we noted earlier, some Cancer Services Managers and Consultants thought PCCLs in general had much more say about commissioning than most PCCLs actually had.

On the positive side, some PCCLs regarded the Network as being *'really useful'*, *'very valuable.'* They particularly appreciated getting to know acute sector clinicians and being able to exchange views with them. There were cases of PCCLs speaking with great satisfaction of how they had begun to get hold of the overall picture, or how much they had learned about the primary/secondary interface (the tertiary was seldom mentioned). They relished situations where they had persuaded hospital specialists to take more account of the realities of primary care, and being recognised as having their own sphere of expertise. The Director of one Network said that PCCLs had certainly helped to *'raise the profile of prevention … of screening … of smoking cessation … and of communication between primary and secondary care.'* She also mentioned that *PCCLs 'have a particular role in relation to general palliative care. We tend to get a bit focused on specialist palliative care and they remind you that there's a huge number of people who don't need specialist palliative care, but need palliative care nevertheless.*'

As well as playing an educational role, some PCCLs savoured playing a part in battles over funding, though being caught up in such feuds could also be unpleasant - and not just because of the intensity of argument. There were grave misgivings about how funding decisions were being made, and a sense of unfair dealings came through in some cases. This was exacerbated by frustration at being expected to negotiate *'when the goalposts were constantly changing and were not always clear to the clinicians on the ground.'*

In contrast to those who found their feet in Networks, many PCCLs struggled to come to grips with what goes on in them, or found acute-sector dominance of Networks off-putting, or thought that their limited time was better spent on more local interventions. This was a matter of concern to some of the other people involved. One Network Director thought that PCCL attendance was less than 50% *'and only three or four of them have the commitment or understanding to really contribute to the Network*.' He put this down to two factors mainly: Failure by PCTs to give PCCLs enough support and status, and the dynamics of Network meetings.

> *'Some of it's the nature of things being discussed. Because it's what they do [i.e. hospital clinicians], the groups tend to focus on specialist care … GPs are more interested in interface management than in the niceties of specialist care, so if a GP who is a very busy looks at the agenda for a meeting and can't see anything on it that he's going to be interested in or able to contribute to then they won't turn up. If they don't turn up, they don't produce an agenda that reflects their own interests, so you enter a cycle of decline.'* (Network Director)

An Oncologist in that Network worried that PCCLs were not at least present when reconfiguration of services was being discussed, *'so they would have a feel for how services are being developed.'* Various interviewees mentioned that primary care was little understood among the people who tended to be most influential at Networks, and there was even less understanding of public health issues - although some Networks seemed to be overcoming this. As one PCCL put it:

> *'When you work at a high level secondary care hospital or teaching hospital you want to be doing really good and innovative things, and that sometimes means caring for cancer in really unusual and different ways, but it sometimes means that the bottom line gets forgotten, and actually public health and general practice get so confused.'*

These problems could be compounded by unrealistic expectations regarding PCCLs' knowledge of cancer or their authority within their own PCTs. A Network Director who thought PCCLs were making a positive impact nonetheless questioned - with GPs mainly in mind - how representative they were:

> *'I think they don't represent the PCT in its entirety - PCTs still are quite divided organisations. I think what they do represent is the GP voice in the way that any GP can represent another GP. I mean, GPs, if you know their culture, are very individualistic, and whereas a manager can genuinely represent the other managers, it's a much weaker kind of representation with GPs. But they do … give you an indication of how GPs think and what their problems and priorities are, which actually tend to be the same across the patch regardless of the PCT.'*

That line of thinking also raised the question whether there were better alternatives to each PCT having its own PCCL (as was intended), particularly when the difficulties of fulfilling the remit as it stands were also taken into account. At least there needed to be a more structured approach to co-ordinating PCCLs. The Network Director just quoted thought that appointing a Lead PCCL, paid £5,000 on top of the national amount, *'has* *been the single most useful thing that we've done.'* Some PCCLs would go further and were in favour of working across PCTs:

> *'the more general practice takes on, it's probably not realistic to have five [PCCLs] for one city … there would have to be one CHD Lead for the city, one mental health Lead, and so on, otherwise you would not get the level of expertise. If someone is going to be a Lead, they really need to know their stuff … and spend a significant amount of their time working in both primary and secondary environments … otherwise credibility would be an issue.'*

A PCCL from another area wondered whether the PCCL role would have *'sat better with the Network than the PCTs'* and that it would be more productive to pool the funding and have two or three clinical leads covering a whole Network.

Against that were the arguments for not tinkering with the role until it has been given time to bed in. However, some PCTs might let the role lapse unless there is dedicated funding for it. This has implications for Networks too.

> *'I think it would be very difficult to get primary care to interact with us if there was no financial support because we could not legitimately say "We would like you at this meeting or that you must have a plan for cancer services" … they simply would not be able to do it. It is an enormous threat if we don't support [PCCLs] with financial incentives … It would be a backward step if we withdrew the funding from this group of people.'* (Network Director)

That may well be, but given the relatively small amounts of money involved, it seems far more important for Networks to resolve the fundamental problems of mistrust in regard to commissioning. As one PCCL put it:

> *'The network is a very elaborate mechanism and it's got very unwieldy. What it has done is brought the commissioners and providers together and there is some agreement on policy on chemotherapy and management of tumours, and that's good. But it hasn't been translated into commissioning of services … Decisions could be much simpler … [and] I think there needs to be a designated cancer budget … [so, among other things, there can be] greater transparency about where the monies are going.'*

That indirectly reinforced the need, noted earlier, for integrated planning of services, without which talk of integrated care is wishful thinking. That was not covered in any depth in the interviews, but questions of how the PCCL's role could best be linked with others was discussed, in particular the potential for multi-disciplinary approaches, so we will look at views about that in a moment.

Two minor points can be dealt with before moving on. First, there was the multiplicity of meetings. A couple of clues suggested that Network meetings were scheduled to suit hospital clinicians, and the pressures on practising PCCLs were not taken into account as much as they could be. Furthermore, it would ease those pressures, and help PCCLs to feel more respected, if the convenors of meetings were much more circumspect about expecting PCCLs to attend - apart from when their input had some priority. It would help just as much if all PCCLs collaborated more to divide up this part of workload, as some of them do. Yet some tolerance of meetings comes with the territory, so a skilful approach is called for. It also has implications for choosing PCCLs. As one of them pointed out, someone with a purely clinical cast of mind would find it hard to cope with a lot of quasi-managerial discussions. Another speculated that it might be a good idea to get somebody with no particular interest in cancer to go to meetings, because they would have a fresh slant on it.

The second issue is not unrelated - the PCCL's role vis-à-vis user representatives and patient and carer groups. Four user representatives were interviewed. Two of them had only the haziest notion of the PCCL's remit. Running through the interviews as a whole, there were some suggestions that PCCLs should try to have more contact with cancer support groups, whether at the groups' initiative or the PCCLs'. On the other hand, there was widespread concern about PCCLs being over-burdened, and as things stand it seems quite unrealistic to expect them to take on more involvement with support groups. As one User Representative put it:

> *'To be honest, most patients would not be particularly interested [in knowing about the PCCL]. They are really only interested in their treatment. As long as the system is working for them - as long as the cancer leads are being effective - then patients probably don't need to know.'*

These views were reiterated in the Postal Survey responses and in the patient and user views collected at the NDP Partnership Forum at the Heathrow meeting mentioned earlier (Section 3 of this Report).

7.6. Linking the PCCL role with others:

The issue of linking the PCCL role with others was raised in two different ways. One was whether, in principle, the role should be combined with another, such as clinical leadership for CHD. The second was whether a multi-disciplinary approach would be appropriate.

We will deal first with the question of combining roles because views on it were clear-cut. Oddly enough, of those with whom we raised this, the only ones who did not dismiss the idea were a Consultant Oncologist and a User Representative. The Oncologist saw *'no fundamental reason … why it shouldn't be, it's just a question of how much work they've got to do*,' and how clinical leads collaborated to manage committee-work. Another Oncologist would have none of this: *'Absolutely not'* – if cancer were combined with heart disease, the clinical leads would *'just become administrators and de-skill themselves.'* Almost all interviewees who gave an opinion on this were totally opposed to combining cancer with another clinical leadership role, because it would be unmanageable and detrimental to clinical leadership in either capacity.

> *'CHD can be combined with diabetes because they've got similar issues, but cancer is completely different.'*
>
> *'They're two separate networks, with no mutual support between them, so if a person is already having difficulty handling one, I don't see how getting them to do two is going to hel.p.'*

On the second question, however, opinion was much more in line with the PCCL who said: *'I don't think the PCCL role should stay as it is. I think we need to work more as a team – but that will involve more investment and infrastructure*.'

Teamworking infrastructures: There was support from all quarters for multi-disciplinary or teamworking approaches – so long as the enabling infrastructures were put in place. However, people had different ideas about what 'working more as a team' meant in practice, and some regarded it as being beyond existing capacity.

> *'Yes if it's clinicians and managers working together'* (PCCL)
>
> *'I think they [PCCLs] need to work through a team of nurses and managers'* (DPH)

> *'the infrastructure at practice level isn't in place'* (PCCL)
>
> *'In an ideal world, yes, but you are talking about PCTs which are very short of capacity'* (DPH)
>
> *'You'd get much more done, you'd have different ways of looking at things, and you'd be able to work across the organization more effectively.'* (PCCL)
>
> *'I think we've got the nucleus of a more multi-disciplinary approach … by having a nurse and GP working closely together … The direction we need to move in [is] multi-disciplinary across both acute and community.'* (DPH)

Notes of caution were being sounded, by people keen on going in this direction as well as by those wary of collaborative working.

> *'I think the leadership role should rest with one person. They should be the lead of the clinical team and not just an esoteric function, and that team should include representatives of other components of cancer care, including community nursing and palliative care. But I don't think the PCCL role itself should be split up.'* (Network Director)
>
> *'It would not work with the resources we have now – You definitely need a manager.'* (PCCL)
>
> *'You've got network teams, and various other teams. I'm not sure that you need yet another team.'* (Lead Cancer Nurse)
>
> *'the tumour board meetings I attend are like multi-disciplinary teams. I don't think we need to form any more groups I think there are quite enough of them around already. I am anti meetings for meetings-sake.'* (PCCL)
>
> *'The team approach would be nice but the problem with any group is getting them to meet.'* (DPH)
>
> *'No, I think that's the problem with the health service at the moment, too many teams of managers. They need to get someone to get on with the job, and give them a bit of secretarial support.'* (GpwSI)
>
> *'We're in danger of having a Lead for everything.'* (DPH)
>
> *'I would hate to see a particular model being imposed nationally … That would be distinctly unhelpful.'* (Chief Executive)
>
> *'It would certainly be an option to consider but we're an average-sized sort of PCT, and we find it really hard to sustain the GP Cancer Lead to be honest. For every Cancer Lead there's got to be a CHD Lead and a Mental Health Lead, and with the constraints that we have I don't think we'd be able to sustain more than what we've got at the moment – and that's pretty ropey to be honest.'* (DPH)

Other very pertinent concerns were raised when discussing the PCCL remit and the need to build a supportive infrastructure for any clinical leadership role. The DPH who remarked that *'We have to make our minds up whether we want GPs to develop managerial skills and spend their time being managers, or whether we want to actually use them for what they're good at, which is being doctors'* was all in favour of teamworking approaches so long as the infrastructure was there to manage implementation. General concerns about under-resourced initiatives were heightened in this case precisely because PCCLs were introduced with so little provision for infrastructure support.

Putting infrastructures in place: Nevertheless, some PCTs have managed to put supportive structures in place. Considering the six case study areas, it appears that determined commitment by a few individuals who had collaborated to make things happen was the main factor that accounted for this. As already noted, some PCTs were taking clinical leadership much more seriously than others, and that seemed to be independent of which Network they were in. Of course, the degree to which they had developed supportive structures also varied. The following quotes come from PCCLs in three different Networks, and are chosen to represent the efforts being made by certain PCTs and the kind of thinking that underpins them.

> *'In our PCT we've got two GPs, a manager and a nurse, and I think it's a good model actually but we endlessly struggle to enable the nurse to have back-fill time. I'm a part-time GP so it's actually quite easy for me to fit it in and around other things.'*
>
> *'An individual Cancer Lead – no matter if it's a GP, a nurse or a manager – can't deliver the NHS Cancer Plan in a PCT. We've got what we call a local implementation group, with basically a lead manager and a lead doctor from both Acute Trusts and from the PCT working together to try and deliver the agenda. So yes, you very much need a team to do it.'*
>
> *'You have to accept that the clinical cancer lead is one of a part of a team which has people who can finish the job for them. I am one of a team of people that work on cancer in our PCT, so I have a screening and commissioning manager, I have got the public health person, I have got the health improvement person. Because I have successfully bid for money I also have a project manager … There is no good in having five people who rub each other up the wrong way. If you are going to have a team of primary care people it maybe does not always have to be GPs, maybe some can be practice nurses, some need to be managers.'*

As forums for coordinating cancer care across health economies, the dynamics of Cancer Action Groups in one of the case study sites, were immediately relevant for PCCLs, perhaps more so than Networks. *'That's where we decide our priorities and what we're going to invest in, whether it be in primary care, in secondary care or tertiary services'* was how a Cancer Improvement Manager described their role, yet also admitted that the Group could be in the position of having to make very difficult decisions, only to find later that the funding was not in there. That kind of reversal was bound to strain relationships and group dynamics, hard enough in the first place for multi-disciplinary and multi-agency groupings. A DPH gave some reasons why their Cancer Action Group was regarded as a model of cohesion and pulling together:

> *'it's about setting a tone, and having high expectations for how people work … being very clear about what we're trying to achieve, regular reporting on progress, and naming and shaming when people don't do what they are meant to do … It's not rocket science.'* (DPH)

A notable feature of that particular situation was that the PCT and Acute Trust jointly appointed a designated support manager for cancer. The PCCL in that case waived their additional income to help fund the post. The support structure also included a commissioning lead on cancer, and administrative support specifically for the PCCL. *'So we all play our part in different ways.'* As A DPH from another part of the country said,

> *'The critical thing is how [PCCLs] operate as part of a network. My personal view is that it doesn't matter what you put down on paper, what you're looking for is talented innovative leadership and the ability to work with others. If you get those people in a room together, they will work out between them the best ways to make things happen. The fact that there is a dedicated individual with ring-fenced funding is what has enabled me to create capacity.'*

Regardless of how everything else worked around them, the keystones of an effective infrastructure was a cancer lead clinician fully supported by a lead manager for cancer.

Choice of PCCL: For most people concerned, those infrastructural keystones mattered more than whether the PCCL was a GP, a Nurse or someone else. However, there was a division of views as to which it should be, and the split was not consistently on professional lines. The arguments centred around competing notions of credibility via-a-vis one's colleagues in primary care and one's counterparts in the Acute sector. The following points sum it all up

> *'It does not matter so much whether it's a GP or a nurse, as long as they've got enthusiasm and commitment and a bit of drive.'* (Director of Planning)

> *'It doesn't have to be GP-led but I think there should be some doctor input, otherwise GPs get these pathways imposed on them without any input.'* (GP)

> *'I don't know that having a medical background is necessary. I think whoever does it just has to have a feel for the services and be au-fait with what happens in primary care and in hospitals, and how the two join together.'* (Consultant Oncologist)

> *'you're more likely to have clout if you're also medically qualified. Having said that, I know a lot of nurses are doing the job very well.'* (PCCL, GP)

> *'The only thing I'm not sure of is if someone comes purely from a general practice background how much the secondary care people are going to listen to them.'* (GpwSI)

> *'I think it would be a very unusual nurse who could really deliver and stand up to those hospital consultants at that level. The other problem if they are a practice nurse they understand how primary care works operationally, but most don't do much management. The person who does it has to have an individual patient workload that involves patients with cancer. There are commissioners who are managers who do a good job but I think the primary care lead role cannot be done by a manager.'* (PCCL, GP)

> *'The GP is one of the few constant figures for the patients … Management does come and go unfortunately, there does seem to be more of a turn over. We are a constant in people's lives.'* (PCCL, GP)

> *'Doctors are always the best to do these jobs, as long as they have the requisite leadership skills … Doctors listen to doctors basically. Other professionals can do it with excellent leadership skills but it takes excellent leadership skills to take the doctors with you. Doctors give you a head start.'* (DPH)

> *'I don't think it's essential to be a GP. I'd be worried, however, if a significant number weren't.'*(Consultant Oncologist)

> *'The ideal background is public health, because you come in with the population health knowledge, knowledge of health service organisation and management, don't have a particular vested interest in a particular mode of treatment or aspect of cancer care, so you're not pushing palliative care or scanners or particular kinds of oncology at the expense of the overall picture.'* (DPH, Consultant in Public Health)

Two of the three Nurse PCCLs we interviewed had been uneasy because of their background. One described feeling 'on the back foot' when two-week waits came in, because she didn't have the knowledge to help facilitate it. The Cancer Services Manager in her area mentioned that as a problem too, but also said that as someone with a nonmedical background herself, she was slow to question medical things too. On the other hand, she thought that:

> '*having nurses in post has contributed to very much focusing on improving palliative care, and also cancer prevention, and that's where the nurses have come into their own in those discussions with patients and that kind of information sharing rather than by being the link between primary and secondary.'*

A narrowing of the remit was strongly evident there, but then, as we have seen, some GP PCCLs had focused mainly on primary palliative care. Another Nurse PCCL said that, even though she was very confident with nursing and community colleagues, *'I did have concerns about working with GPs because, with the best will in the world, GPs are a difficult group to engage with.'* She also felt a lack of respect for her role as PCCL outside the practice she dealt with as part of her normal work, not to mention further afield. The third Nurse PCCL was more sure of her general approach:

> *'I think it's around being able to deliver what you say you're going to delivery and also supporting them in being able to deliver from their end as well. If you don't do what you say you're going to do then obviously you will loose face with them. I think having a clinical background has helped as well, and the fact that I've worked with GPs in the past also helps because I've got an idea of how they think and the sort of things they will and won't accept, so therefore you use your influence skills around that knowledge base.'*

On the general issue, a Network Director who had worked with both GP and Nurse PCCLs thought that *'The GP, if I can generalise, … can really only talk with his own practice hat on, unless we're doing a specific project that requires him to go out and get feedback,'* whereas nurses with general roles such as clinical governance or work that took them around various practices were more likely to have a better overview across the PCT. The conclusion we draw from this debate is that, along with supportive infrastructures, most PCCLs need individual support, particularly from their Chief Executives/senior colleagues. Training programmes can only do so much, and for this kind of role it is hard to beat informal coaching or mentoring.

7.7. Conclusions:

The pattern of findings from the six case study sites suggests that this stratified sample is representative of opinion across the board with regard to PCCLs and the views expressed are in line with the findings from the Postal Survey. By our own classification of the overall tenor of their views, almost 50 per cent of the people interviewed were strongly or broadly in favour of PCCLs, just over one third were in favour but had misgivings, and one eighth of the interviewees were more doubtful than favourable or highly critical. (Rounded, the proportions were 49%, 35% and 13% respectively, with a few not in a position to judge.) This means that the initiative had considerable support, with a small number of sceptics who had concerns about the nature of the remit and lack of back up for the post.

On the issue of whether PCCLs have had an appreciable impact, most of the current or former PCCLs interviewed thought they had had *some* significant impact – by raising the profile of cancer within their PCTs, by forging links with Networks and secondary care providers, or by helping to meet service improvement targets. However, a sizeable minority of PCCLs – roughly one quarter to one-third – doubted they had had any real impact, and opinion was similarly mixed among the other people to whom we spoke. Among PCCLs who felt they were not making much of an impact, common themes were that they had had to spread themselves too thinly because the remit was too broad, that lack of support had made the task impossible, that lip service was being paid to them and cancer was not a priority for PCTs.

The PCCL remit: In general, the way the remit is described suggests widespread uncertainty about it. This was as much the case among current or ex-PCCLs as it was among the other respondents. Different understandings of the role surfaced irrespective of whether PCCLs were in the same or different Cancer Networks, and regardless of whether the post was held by a GP or Nurse. Two kinds of interpretation were particularly evident. One was the view that the remit is vague or unwieldy, so it is up to PCCLs to figure out for themselves how to make it workable. The other was an implicit understanding that, in the absence of a consensus as to what PCCLs were meant to be doing, what made their activities coherent was the fact that the PCCL was doing them. Both interpretations tended to regard the remit as being how the role was being performed – essentially the job was what the PCCL made of it.

It was striking, for instance, that among senior colleagues with whom PCCLs were working closely, there was no discernable consensus about the 'strategic' aspect of the remit, set out in the first line of the job description. The division of opinion on this greatly affected how the role was perceived. The crux of the matter seemed to be this. As some saw it, overall strategy had been set out in the NHS Cancer Plan; commissioning decisions were taken by PCTs, so PCCLs should focus their efforts on improving clinical practice and liaison with secondary care. A second group favoured a re-distribution of cancer care resources to take account of the fact that, notwithstanding the importance of hospital treatment, cancer care happens mostly in primary care settings – and PCTs are responsible for preventative strategies. This group saw PCCLs as being at the forefront of such a re-alignment of priorities, and therefore they wanted PCCLs to have more say in regard to commissioning. A third group stood at the intersection of those views, tending to frame strategy – and the PCCL role – in terms of the interface between primary and secondary care. These competing agendas intersect with debate about the nature of clinical leadership and the extent to which clinicians should be directly involved in managing change, not to mention in this case the manifold implications of cancer. On top of all that, the introduction of the scheme coincided with the organisational upheaval when PCTs were just finding their feet.

All this put a premium on the clarity and feasibility of the PCCL remit. The balance of opinion was that the brief was not as clear as it should have been, and that it needs to be more tightly focused. There was too much to do in the time available, and there appear to have been assumptions about the general level of support for clinical leadership and the level of priority given to cancer. Sharpening the focus would help to resolve the problem of overlaps between the PCCL remit and other roles in primary care cancer.

Linking the PCCL role with others: The issue of linking the PCCL role with others was raised in two different ways. One was whether, in principle, the role should be combined with another, such as CHD. The second was whether a multi-disciplinary approach would be appropriate. Almost all interviewees who gave an opinion on this were opposed to combining cancer with another clinical leadership role, because it would be unmanageable and detrimental to clinical leadership in either capacity. There was support from all quarters for multi-disciplinary or teamworking approaches – so long as the enabling infrastructures were put in place. However, people had different ideas about what 'working more as a team' meant in practice, and some regarded it as being beyond existing capacity.

Against the general lack of infrastructure support, some PCTs had put supportive structures in place. Considering the six case study areas, the determined commitment by a few individuals who have collaborated to make things happen was the main factor that accounted for this. Some PCTs were taking clinical leadership much more seriously than others, and that seemed to be independent of which Network they were in, and the degree to which they had developed supportive structures also varied.

Regardless of how everything else works around them, the keystones of an effective infrastructure were a cancer lead clinician fully supported by a lead manager for cancer. Integrated service planning should be the prime focus of their joint efforts, since it is the prerequisite of integrated delivery. Adopting that kind of focus would also help to resolve the problem of trying to be 'strategic' in contexts where there is little organisational capacity for strategic thinking or a tendency to narrow the remit down to palliative care. Moreover, the combined effect of sharpening the focus of the PCCL role and giving it real 'clout' was also likely to facilitate more focused collaboration between the primary and acute sectors. Another consideration is that all these factors should count for more than having to be on the PEC or PCT Board to be in the decision-making 'loop'.

Opinion was divided about Network participation. Some PCCLs regarded it as well worthwhile, and probably were correspondingly active in their Networks. In contrast to those who found their feet in Networks, many PCCLs struggled to come to grips with what goes on in them, or found acute-sector dominance of Networks off-putting, or thought that their limited time was better spent on more local interventions.

The ability of PCCLs to fulfill their contribution to Networks can also be undermined by unrealistic expectations regarding their knowledge of cancer or their authority to represent their PCTs. The question of 'clout' can be further complicated by the view that GPs tend to speak only for other GPs and their concerns were similar regardless of which PCT they came from. That line of thinking also raised the question whether there are better alternatives to each PCT having its own PCCL, particularly when the need for infrastructural support is taken into account, and the possibility that some PCTs might let the post lapse. At least there needs to be a more structured approach to co-ordinating

PCCLs, perhaps by following the example of the Network that funded a Lead PCCL. Some PCCLs were in favour of working across PCTs or pooling of funding to have two or three full-time clinical leads covering a whole Network. Against that are the arguments for not tinkering with the role until it has been given time to bed in.

'Early days yet': Notwithstanding the issues outlined, most of the people interviewed wanted the PCCL role to be more sharply focused and developed rather than discontinued. The main consensus, was that it is 'early days yet' and the initiative needs to be allowed to take hold. The specific remit and infrastructure do not have to be the same across the country, but the post as well as the person holding it must have local credibility.

8. Discussion

The Discussion is centred around the Objectives of the study, which can be found in Section 2 of this Report. Each Objective is set out below as a heading and the relevant points from the Report are collected together so providing a summary of the main study conclusions. The Key Findings are then summarised in a section headed 'Key Findings' at the beginning of the Report.

8.1. To examine the extent and nature of PCTs' use of PCCLs:

The use made by PCTs of PCCLs varied hugely, with some PCTs being scarcely aware of them or ignoring them. Others, however, have been aware of the importance of providing a supportive environment in order to get the most out of the role and their investment in it. In a supportive environment – with access to facilities such as secretarial, administrative and/or managerial support – so much more can be achieved since PCCLs need to spend much less of their time in building up relationships within and outwith the PCT. Essentially, they had a head start.

It is very clear that PCCLs spend an enormous part of their time attending meetings at all levels, both within the PCT and elsewhere. However, this is not necessarily a bad thing and could be a reflection of their strategic role - receiving and passing on information about cancer services and their development, making themselves more widely known and promoting the cause of primary care cancer. The strategic role means that they operate one or more steps removed from patient care. Nevertheless, the strategic element of the PCCL job description was frequently described in rather hazy terms with many different interpretations of what it actually meant.

How PEC membership could improve their role and give them a voice on the PCT was important for some PCCLs, and should be noted by PCTs. Interestingly, however, the PCT managers rarely mentioned PEC membership as a factor.

There is no doubt that those who were on the PEC felt that it was helpful to their cause. Others, however, noted that being on the PEC in a tokenistic manner and not being listened to was even worse. Some of those not on the PEC, who had no desire to be so, tended to be those whose status was assured in the PCT and more widely in the local health economy. For them, being on the PEC was irrelevant.

Ways in which PCCLs had contributed to the PCT were in acting in an advisory capacity, in forward planning, developing cancer care pathways and commissioning and audit. The aspect of cancer care that PCCLs had concentrated on was palliative care and the GSF. This is the aspect of cancer care most often identified with primary care. However, there are many other neglected areas of cancer care in the primary sector and it would be disappointing if PCCLs did not move more into those areas too, when time permits.

One way forward would be to embed the role more closely with PCT management and support infrastructure, as well as sharpening the focus of the remit to promote clarity and avoid overlap with others with a cancer remit in the PCT.

8.2. To examine the level of national and local service improvements attributable to the PCCLs:

Most PCCLs knew what their local and national cancer targets were. As mentioned above, PCCLs were focusing predominantly on palliative care. Other areas of focus identified were improving communication and early diagnosis and referral, and these were the areas that the PCCLs also thought that they had the most impact on. Most PCCLs did think that they had contributed to raising standards of care and hence contributing to service improvements, by means of raising the profile of primary care cancer at all levels. This had led to improvements to palliative care services, shorter waits and improved communication at all levels. However, it was still early days and greater contributions are likely in the following years as PCCLs consolidate their role within PCTs.

There is no doubt that PCCLs can find it problematic to influence strategy and raise standards, as can be seen with the difficulties cited in engaging GP practices in Baseline Assessment which, once completed, should help in local planning and distribution of resources. This might be where PCCLs can influence strategy by contributing to the development of integrated care pathways from primary to secondary to tertiary care.

8.3.To explore progress on the five strategic elements of the PCCL Job Description:

The details of the Job Description can be seen in Appendix 3.

1. To provide strategic leadership within the PCO in line with the NHS Cancer Plan to develop services for cancer patients:

- Although PCTs were encouraged to add to the single session per week funded by the Department of Health, most did not do so. PCCLs, therefore, had only 3-4 hours of funded time per week available to them and cannot achieve everything in such a large remit.
- Most PCCLs were proceeding with either implementing or rolling out Baseline Assessment.
- There was some concern about the quality of the baseline data from practices: it was of variable quality and frequently under-developed.
- Baseline data proved problematic to collect since it was frequently difficult to engage GP practices in data collection.
- PCCLs were reasonably happy with the guidance they had received on Baseline Assessment.
- Success in Baseline Assessment was identified as one of the key achievements of the PCCLs.
- Prevention and screening strategies did not feature highly, but this may change in the future.
- Early diagnosis and monitoring of the 'two week rule' were identified as important aspects of PCCL workload.
- Progress with 'two week waits' was one of the PCCLs' key achievements.

2. To contribute to the development of Network service delivery plans in order to streamline patient care (using the 'care pathway' approach):

- Most PCCLs attended Network meetings.
- PCCLs noted a lack of guidance on lung cancer pathways.
- Palliative care and patient care pathways were important aspects of the PCCL role. There was significant input into this aspect of primary care cancer.

- Cancer services commissioning was being focused on by PCCLs, but at a much lower level than palliative care, early diagnosis and referral. Some had found it difficult to get involved in commissioning.
- Little guidance had been given on feeding back local initiatives to Macmillan. Feedback was not widespread or regular.

3. To contribute to Network development and, where appropriate, to represent the PCO and primary care in the Cancer Network:

- Most PCCLs represented their PCO and primary care at Network level.
- Raising awareness of primary care cancer was identified by PCCLs as one of their key achievements, at Network level and elsewhere.

4. To raise standards of cancer care within the PCO in collaboration with the clinical governance lead:

- PCCLs attached some importance to working with the PCT clinical governance lead.
- Many PCCLs felt they had raised the standard of cancer care in their PCT, as did the PCT managers, primarily by raising awareness of primary care's contribution to cancer care, and by their promotion of palliative care and GSF.
- Establishment of cancer datasets was problematic because of lack of engagement by many GPs. However, the requirements of the new GMS contract may change this.
- PCCLs indicated that they had received very little guidance on implementing quality assurance, which did not feature highly in their activities.

5. To ensure that services are responsive to the needs of people affected by cancer:

- Many PCCLs have made contact with local user groups and others had plans in place to do so.
- Awareness of all aspects of the Macmillan Support Programme (which included frequent references to and specific information and resources about how to

involve people affected by cancer in the design and development of services) was almost universal amongst PCCLs.

- Attendance at CLS events (where learning was often shared concerning how best to involve people affected by cancer in the design and development of services) averaged 50-60%.

In summary, the PCCLs had made considerable inroads into many aspects of the Job Description.

8.4.To identify characteristics of PCCLs that have ensured their effectiveness, and how these change over time:

The most important personal attributes that PCCLs identified were communication skills, enthusiasm, knowledge and persistence, as well as good relationships with colleagues. These were closely paralleled by the views of the PCT managers. In fact, being known locally in a long-standing capacity was important in providing local credibility and acceptance and served to facilitate the role. Assertiveness was important as well, but was not always necessary in PCTs where staff were receptive to the role and were prepared to be supportive and facilitative. Understanding strategy was vital.

The role had clearly changed over time, becoming more focused as well as expanding beyond the PCT, with greater commissioning involvement. One important way in which the effectiveness of PCCLs might be increased is by allowing more time to be devoted to the role. Ensuring key individuals were aware of the post and its intentions would also be of considerable help in allowing PCCLs to move forward without having to first explain themselves, and would facilitate the building of relationships. It is this that has so occupied many PCCLs in their early years and meant that their real work of developing strategy had been limited. Those who had previous experience, perhaps in commissioning or as PEC Chair, and were used to thinking strategically appear to have particularly enjoyed the role, emphasising further the significance of the ability to take a strategic viewpoint. These previous experiences may have provided the head start at PCT, Network and Acute Trust level, which is so important. Three years is not long, and is even shorter if much time is taken up in building relationships. Local knowledge, credibility and the ability to take a strategic standpoint are significant. Most PCCLs are

GPs, but this is not a prerequisite and the attributes required are not exclusive to GPs, though being a GP may help.

8.5.To examine the impact of the PCCLs' clinical background on how they perform their role:

Whether the PCCL is a GP, Nurse or other health professional is less important than having local credibility. Some thought that even a clinical background was not always necessary, as long as the PCCL was aware of what happens in primary and secondary care. However, a medical background was thought to provide credibility in primary care, though much less so in secondary care. Others thought that GPs had a head start in that other doctors would listen to them. Nurses too had their supporters. They provide a different focus, which might be more in tune with what PCTs wanted. Interestingly, some nurses commented about feeling daunted at times in some meetings; but some GPs also felt daunted in hospital trust meetings.

8.6.To identify the factors associated with the successful achievement of the PCCL role:

The key achievements that were identified by the PCCLs themselves are interesting in that they reflect the problems that they have had in starting out in a new role where other key individuals were less well informed than might have been expected. As a consequence, key achievements were associated with developing relationships locally and raising awareness of primary care cancer. These are the sorts of achievements to be expected in the early phases of a new initiative. Other achievements were more specifically task orientated, including progress with Baseline Assessment, out of hours, palliative care and two week waits. These achievements were also those identified by PCT managers except that they placed greater emphasis on palliative care, perhaps reflecting a more goal oriented approach and a lack of awareness of some of the difficulties facing PCCLs within their PCTs.

The factors associated with key achievements included prior knowledge of the local health economy, which enabled the initial phase of building relationships to proceed more quickly; and local credibility, which again acted in a facilitation capacity.

The importance of adequate support was again raised in this context. Those who had identifiable support at PCT, Cancer Network, and from the Macmillan Support Programme found their role much easier to fulfil. The Macmillan Support Programme provided essential information and knowledge to allow them to proceed with confidence. PCCLs themselves also thought that PEC membership was extremely important, although this was not shared by PCT managers. Dedicated funded time was also seen as essential to the achievement of the role, coupled with the personal skills of the post holder – in particular their commitment, determination and personal application to the role.

Needless to say, there were barriers. These tended to reflect the factors associated with success. Engaging others, especially GPs, was particularly trying, making achievement of the Baseline Assessment difficult. Cancer was not always high on GPs' agendas. There could be a lack of awareness at all levels of what the PCCL role entailed, and a lack of communication with the PCT, Cancer Network and secondary care that slowed down any progress that might have been made. Lack of time was a universal complaint, reflecting the extensive nature of the PCCL job description. However, time might not be a factor if the requirements of the post were channelled appropriately instead of having to attempt to fulfil the entire remit. Indeed, some PCCLs commented that they felt they were spreading themselves too thinly, and hence having less of an impact than they might have hoped for.

8.7.To examine the impact of relations with PCTs, Cancer Networks and local GPs on the PCCL role:

Support was key to PCCLs. Many did receive support from their PCTs, although a minority did not, with some dissatisfaction being expressed. Support could be shown in terms of the environment in which the PCCL worked and in terms of the infrastructure provided.

A high level of support to the PCCLs who were GPs came from their own practices, many of which used the PCCLs' knowledge to the benefit of the practice. Macmillan was also seen as supportive. But local GPs and nurses were described as much less supportive - even obstructive - making Baseline Assessment particularly difficult.

Contact and collaboration with key individuals was extremely important to PCCLs, particularly with the Network, hospice, the palliative care lead, secondary care clinicians and commissioning managers.

Notably, over three quarters of PCCLs represented their PCT at Network meetings and two thirds had helped to develop service delivery plans. However, whether this attendance at Network meetings was as a fully integrated member or merely tokenistic varied from Network to Network. Those who felt integrated achieved a great deal and were able to promote primary care; others were less happy and could be daunted by the secondary care ethos of Networks. Trying to represent the PCT on the Network could be difficult, particularly when the PCT itself was not supportive or cancer orientated.

8.8.To examine the impact of the Macmillan Support Programme on PCCL effectiveness and identification of any changes that might be required:

A well-designed curriculum was put together by Macmillan Cancer Relief which exhibited considerable foresight in anticipating PCCL educational and support requirements. For those PCCLs who used it, the Macmillan Support Programme Collective Learning Sets were highly regarded as a place to discuss successes and problems with peers. This was essential, at least initially, because many PCCLs had little idea of what was expected of them.

However, despite the enthusiasm for CLSs exhibited throughout this Report, attendance rates were not always particularly high and the Macmillan Support Providers spent considerable time trying to track down new recruits, sometimes unsuccessfully. It is likely that time was a factor, however, with some PCCLs wanting to attend more frequently but not having the time, for what is a voluntary programme.

Some aspects of the programme were found to be difficult, especially the personal development plans, a concept outside the remit of most GPs, though less so of the Nurses. Participation did, however, increase over time. Although most PCCLs had heard of all the aspects of the programme, the use that was made of the different parts varied considerably, with the website being particularly under-utilised.

Clearly, the Macmillan Support Programme had a very significant impact on the effectiveness of those PCCLs who used it, especially the CLS. PCCLs particularly rated improvements in their knowledge and collaborative abilities. They attributed improvements in their influencing and negotiating abilities to the Macmillan Support Programme. Despite this, a number of PCCLs were unable to attribute any of their skills improvements to the programme, although for some, it was still early days.

The Macmillan Support Programme is probably of greatest support to PCCLs who are not on the PEC, to help ensure they do not feel too isolated. Those CLSs that work well are clearly important and it would be a shame to disband them, although they could probably run themselves, once established.

8.9.To identify and quantify the costs of providing PCCL services:

The costs of the PCCL initiative have, until 31 March 2004, been borne by the Department of Health with Macmillan Cancer Relief providing the associated support. Subsequently, PCTs will have to decide whether the role should continue, and provide funding if it does. Currently, funding is between £7000-£10000 per PCT per year. It has been estimated that £2000 of additional support has been provided by PCTs and this would be required to sustain the initiative at its current level. In many PCTs, however, PCCLs would benefit from additional resources. This cost is minimal in relation to PCT total budgets. The problem occurs where PCTs are in deficit and need to cut costs. They need to consider very carefully what has already been achieved in a relatively short period of time, and what the future benefits would be of allowing the scheme to continue. Essentially a commitment from the PCTs to continue to fund the PCCL role, and even to extend it, is likely to provide major benefits in the next two years for primary care cancer services.

8.10.To identify how the PCCL role might develop in the future and to make recommendations:

There was almost universal support from the PCCLs and the PCT managers that the PCCL role should continue. How it might develop in the future, and the recommendations arising from this Report are set out in Section 9, which follows.

9. Recommendations

- Primary care cancer is a good choice for the introduction of a 'lead clinician' in primary care, associated with the complexity of the condition and its pathway involving primary, secondary and tertiary care.
- The PCCL scheme has been relatively successful in getting PCCLs up to speed on cancer but now needs to move on.
- It is still 'early days' and the PCCL role needs to be allowed to embed and produce more clearly defined outcomes, as it surely will in the next two years. This is particularly the case since the PCCL scheme started at a time of upheaval in primary care, as PCGs became PCTs, diverting attention from PCCLs.
- There is much enthusiasm from PCCLs and PCT managers that the role should continue. This might be in a different format.

Recommendation 1: The PCCL role should continue. This might be in different formats in different areas.

- The PCCL role does not, however, work well everywhere and innovative solutions are required in some areas.
- One approach might be to expand the sharing of PCCLs across PCTs. PCTs with established PCCLs could 'adopt' PCTs within the same Network that have had recruitment difficulties. Appropriate resources would be required.
- A more co-ordinated and locally responsive approach could help PCTs where PCCL input has been unsuccessful. The 'broad brush' approach might become a more 'targeted' response.
- PCCLs work well in many areas, but in deprived areas there may be other pressing needs, such as ensuring enough GPs for basic patient services. However, if deprived areas do not have a PCCL, they may fall even further behind the more affluent areas, enhancing the 'Inverse Care Law.'[15]
- An approach more tailored to local circumstances might be appropriate in such circumstances. For example, in some areas PCCLs might be based at Network level – perhaps 2 or 3 working across PCTs. Something along these lines already exists in a few places. This model would not be appropriate everywhere, but

could be a solution for those PCTs with high PCCL turnover or inability to recruit.

Recommendation 2: Innovative ways of providing PCCL input, tailored to local circumstances, should be considered in areas with specific problems.

- Where recruitment has been a problem the PCCL role has, in some PCTs, been taken on by existing staff. This has worked well in some PCTs and where this is the case, it should continue. It should not, however, be an addition to the workload of already busy people.

Recommendation 3: PCTs with recruitment problems, where the PCCL role has been taken on by existing staff, should carefully examine their resource input to ensure workloads are equitable.

- Teamworking at PCT level might be the answer in some areas, although lack of capacity at PCT level could be a problem. Ideally a clinician (GP or Nurse) and a manager (the PCT Cancer Lead?) might make up an informal partnership contributing complementary skills. This already happens in some places.
- Consideration should be given to the time constraints identified by many of the study participants. Time might not always be the problem; prioritisation might be required.
- The value of the role has been demonstrated but the size of the remit requires some reconsideration to make it more manageable and to ensure that the real agenda of the role is being pursued.
- Prioritisation should be carried out by PCCLs in all PCTs to reduce PCCLs' tendency to be overwhelmed and to make the Job Description more manageable.

Recommendation 4: Consideration should be given to prioritisation of the PCCL Job Description to make the role more manageable.

- The PCCL role within the PCT requires greater publicity to highlight the merits of the remit and what it is trying to achieve. This is particularly the case in PCTs which have struggled or failed to recruit. However, it is not only at PCT level where the PCCL role requires publicising. This is also necessary, in many areas, at Network, secondary care and GP practice levels.

Recommendation 5: Consideration should be given to making the PCCL role more widely understood at all levels. This could be an activity for PCTs, Networks or for Macmillan.

- PCTs should give consideration to the support they provide for the PCCL. Infrastructure and personal support should be available to all PCCLs.
- Funding and time commitment for non-GP PCCLs needs to be rationalised. If the PCCL role is simply another task on top of an already heavy workload, it will be pushed out. Dedicated time is important.

Recommendation 6: Consideration should be given by PCTs as to whether the practical support they provide to their PCCLs requires reassessment.

- In some areas, Networks have been less than supportive of PCCLs, although it is appreciated they may have competing pressures.

Recommendation 7: Networks should consider ways in which they can provide more support to PCCLs by lowering the barriers to active participation.

- PCCLs have primarily been concerned with palliative care. That is not to say that other aspects of primary care cancer have been neglected. However, it will be important to move forwards into other areas.
- The real remit of the role needs to be debated to ensure that PCCL input is directed towards improving the care that takes place in the primary sector that is not palliative in nature.
- With more patients surviving to require primary care services for longer, cancer could be regarded as a chronic disease and PCTs need to adjust to this.

Recommendation 8: The PCCL remit should incorporate all aspects of primary care cancer.

- The new GMS contract could assist PCCLs in engaging practices, but they may have to sell themselves.

Recommendation 9: PCCLs and PCT managers should consider the opportunities of the new GMS contract and the contribution that PCCLs might make.

- Sometimes, understanding of the strategic nature of the role was confused or lacking.

Recommendation 10: The significance of the strategic nature of the PCCL role should be emphasised, perhaps via the Macmillan Support Programme.

- Care should be taken to ensure that the transition from Department of Health to PCT funding does not demoralise existing PCCLs. Their vast array of informal knowledge needs recognition by PCCLs, PCTs, Networks and Macmillan to ensure it is not lost. This can be achieved by the continuation of the CLS, either with a facilitator, or, for well-established groups, on their own; or at Network level.

Recommendation 11: Care should be taken at all levels to ensure that informal knowledge accumulated by PCCLs is not lost.

- Support for new PCCLs is still essential. Macmillan already has plans in place for the continuation of their Support Programme. Nothing more will be said here about this other than the suggestion that there might be opportunities for established PCCLs to 'adopt' newcomers.

Recommendation 12: Ongoing background and mutual support for PCCLs is still essential, particularly for those new to the role. The Macmillan Support Programme is already planning to continue this support.

The evidence suggests that PCTs are dividing into three *main* groups:

1. *Those that continue to fund the PCCLs:*
    - Where the PCCL scheme is working well
    - Where the PCCL scheme is working less well
2. *Those that discontinue funding the PCCLs:*
3. *Those that have never recruited a PCCL:*

Recommendation 13: PCTs should continue to fund PCCLs.

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Glossary

Baseline Assessment: A tool developed by Macmillan Cancer Relief intended to allow PCCLs to identify local primary care cancer services and patient support in order to be able to establish their local agenda and priorities.

Calman Hine Report (1995): This report outlined the direction in which cancer services in England and Wales should be developed. It recommended a new structure 'based on a network of expertise in cancer care reaching from primary care through Cancer Units in district hospitals to Cancer Centres'.

Collective Learning Set: A method of improving knowledge and capability in a protected learning environment with the opportunity for peer support and encouragement.

Macmillan Support Programme: To provide support for the PCCLs to enable them to fulfil the role and so to accelerate their development towards making an effective contribution to the improvement of cancer services as described in The NHS Cancer Plan.

NHS Cancer Plan: The NHS Cancer Plan was introduced in September 2000 and forms the cancer part of the NHS Plan. For the first time this plan provided a comprehensive strategy for prevention, screening, diagnosis, treatment and care for cancer and the investment needed to deliver these services in terms of improved staffing, equipment, drugs, treatments and information systems and research.

NHS Plan: In July 2000, the Government unveiled a blueprint for reforming and modernising health and social care in England in pursuit of its vision of a modern, patient-centred National Health Service.

The Gold Standards Framework: An initiative jointly supported by Macmillan Cancer Relief and the Cancer Services Collaborative 'Improvement Partnership', as part of their programme to improve the organisation of care for cancer and other palliative care patients in the community in the last twelve months of life.

Appendix 1:

The PCCL Questionnaire

EVALUATION OF THE PRIMARY CARE CANCER LEADS (PCCL) INITIATIVE IN ENGLAND

The views of the PCCLs

This is your opportunity to tell us your views on the PCCL scheme.

This evaluation has been funded by the Department of Health and Macmillan Cancer Relief to help inform decisions about the future role of PCCLs.

Please help us by taking about 20 minutes

to complete the questionnaire.

The information you provide will remain anonymous.

Individual and PCT names will not be attached to any report.

Please return this questionnaire by

Dr Brenda Leese
Reader in Primary Care Research

Professor Phil Heywood
Professor of Primary Care Development

Centre for Research in Primary Care
University of Leeds
71-75 Clarendon Road
Leeds LS2 9PL

SECTION 1: Your role as Primary Care Cancer Lead

1.1. How long have you been in your current PCCL post? . . . . .months

1.2. For how many PCTs are you the PCCL? . . . .

1.3. What is your professional background? *Please tick one box:*

GP *(please specify e.g. partner, salaried, GMS, PMS)* ☐
Nurse (*please specify e.g. practice nurse, HV*) ☐
Other (*please specify*) ☐

. . . .

1.4. Before taking up your present post did you have any special interest in the shaping/delivery of cancer services?

Yes ☐ No ☐

If yes, please describe your experience:

1.5. (a) How many hours a week are you contracted to work as a PCCL? . . . .

(b) Approximately how many hours do you think you work in this role? . . . .

(c) Do you consider your contracted hours are sufficient to achieve all that is required?

Yes ☐ No ☐

(d) *If No*, how many contracted hours/week would you require in the post? . . . .

SECTION 2: How your role as Cancer Lead has developed

2.1(a) What do you consider to be your key achievements since taking up your current post? *Please write in:*

(b) What do you consider to be the THREE main factors that have contributed to these achievements? *Please write in*

2.2 (a) What has been attempted that has worked less well? *Please write in:*

(b). What were the THREE main barriers to achievement that you encountered? *Please write in:*

2.3. What are your priorities for the future as PCCL? *Please write in:*

2.4. Are you:

	Yes	No
A member of the PEC	☐	☐
A member of the PCT board	☐	☐
A member of Cancer Network Executive team	☐	☐
Do you attend:		
PEC meetings	☐	☐
PCT Board meetings	☐	☐
Cancer Network meetings	☐	☐
Other meetings in the PCT (*specify*)	☐	☐

. . . .

2.5. Overall, do you feel supported by your PCT in your PCCL role? *Please circle one number*

Not at all				a great deal
1	2	3	4	5

SECTION 3: Costs of the PCCL scheme

3.1. What is the latest annual allocation of funding to your PCT from the Department of Health for the PCCL role (*if known)?* £. . . . .

3.2. What is this used to support? *Please tick*

	Yes	No	Don't know
PCCL session(s)	☐	☐	☐
Support staff	☐	☐	☐
Office costs	☐	☐	☐
Other *(specify)*	☐	☐	☐

3.3. Are you provided with any of the following as part of your PCCL role: *Please tick*

	Yes	No
Office	☐	☐
Computer	☐	☐
Travel costs	☐	☐
Training costs	☐	☐
Clinic facilities	☐	☐
Secretary	☐	☐
Admin staff	☐	☐
Other *(specify)*	☐	☐

3.4. Can you estimate how much additional resource is provided annually by the PCT for the PCCL role?

(a) Funding *(excluding the annual allocation from DoH)* £. . . . .

(b) Support in kind *(e.g. 2 hours secretarial support/week)*

SECTION 4: Progress with National and Local Targets

4.1. Do you know what are

(a) the local cancer targets in your area?	Yes ☐	No ☐
(b) The national cancer targets?	Yes ☐	No ☐

4.2. What information do you think you should receive about cancer targets? *Please write in:*

4.3. On which issues in cancer care are you focusing?
Please circle one number in each row to indicate priority:

	Low priority			High priority	
Developing preventive services e.g. smoking cessation, healthy eating	1	2	3	4	5
Screening	1	2	3	4	5
Developing follow up services in primary care	1	2	3	4	5
Building/improving communication between primary and secondary care	1	2	3	4	5
Early diagnosis and referral (incl. 2 week waiting target)	1	2	3	4	5
Patient care pathways	1	2	3	4	5
Supportive and palliative care services	1	2	3	4	5
Cancer services commissioning	1	2	3	4	5
Working with Cancer Services Collaborative	1	2	3	4	5
R&D	1	2	3	4	5
Other *(Please specify)*	1	2	3	4	5

4.4. Do you think that you have had any impact on:- *Please circle one number in each row*

	None		Considerable			Not applicable
Developing preventive services e.g. smoking cessation, healthy eating	1	2	3	4	5	☐
Screening	1	2	3	4	5	☐
Developing follow up services in primary care	1	2	3	4	5	☐
Building/improving communication between primary and secondary care	1	2	3	4	5	☐
Early diagnosis and referral (incl. 2 week waiting target)	1	2	3	4	5	☐
Patient care pathways	1	2	3	4	5	☐
Supportive and palliative care services	1	2	3	4	5	☐
Cancer services commissioning	1	2	3	4	5	☐
Working with Cancer Services Collaborative	1	2	3	4	5	☐
R&D	1	2	3	4	5	☐
Other *(please specify)*	1	2	3	4	5	☐

	Poor			Excellent	
4.5. (a) How well developed is the baseline assessment in your PCT(s)?	1	2	3	4	5
(c) How do you rate the quality of the data from practices contributing to the baseline assessment?	1	2	3	4	5

SECTION 5: Extent of collaboration

5.1.(a) How much contact have you had with each of the following?
Please circle one number in each row:

	None at all				Very Considerable
Cancer Network	1	2	3	4	5
Cancer Centre	1	2	3	4	5
Clinical Governance Lead	1	2	3	4	5
Commissioning Manager	1	2	3	4	5
Ethnic minority groups	1	2	3	4	5
Local hospice	1	2	3	4	5
Macmillan GP Facilitators	1	2	3	4	5
Palliative Care Lead	1	2	3	4	5
Patients/user groups	1	2	3	4	5
PEC	1	2	3	4	5
Primary Care Director	1	2	3	4	5
Nursing Director	1	2	3	4	5
Secondary Care Clinicians	1	2	3	4	5
Marie Curie	1	2	3	4	5
Specialist oncology services	1	2	3	4	5
Social services	1	2	3	4	5
Other Local Authority services	1	2	3	4	5

5.1.(b) How important is it for you to work with:-
Please circle one number in each row:

	Not at all				Very Important
Cancer Network	1	2	3	4	5
Cancer Centre	1	2	3	4	5
Clinical Governance Lead	1	2	3	4	5
Commissioning Manager	1	2	3	4	5
Ethnic minority groups	1	2	3	4	5
Local hospice	1	2	3	4	5
Macmillan GP Facilitators	1	2	3	4	5
Palliative Care Lead	1	2	3	4	5
Patients/user groups	1	2	3	4	5
PEC	1	2	3	4	5
Primary Care Director	1	2	3	4	5
Nursing Director	1	2	3	4	5
Secondary Care Clinicians	1	2	3	4	5
Marie Curie	1	2	3	4	5
Specialist oncology services	1	2	3	4	5
Social services	1	2	3	4	5
Other Local Authority services	1	2	3	4	5

5.2. Do you consider you have contributed to raising the standard of cancer care in the PCT?

Yes ☐ No ☐ Don’t know ☐

If yes, please explain how

5.3. Do you think patients will be aware of the existence of PCCLs?

Yes ☐ No ☐ Don’t know ☐

Please explain your response:

5.4. Do you undertake any of the following:-

	Yes	No
Advise on forward planning to the PCT	☐	☐
Advise on commissioning to the PCT	☐	☐
Advise on audit to the PCT	☐	☐
Advise on cancer care pathways to the PCT	☐	☐

5.5. Have you been involved in cancer-related research activities within the PCT?

Yes☐ No☐

If yes, please describe

SECTION 6: Extent of Support

6.1. How supported by the following do you feel in your PCCL work?
Please circle one number in each row:

	No support at all			Very well supported	
Macmillan Cancer Relief	1	2	3	4	5
Local Cancer Network	1	2	3	4	5
PCT	1	2	3	4	5
Local GPs	1	2	3	4	5
Local nurses	1	2	3	4	5
Your own practice*(if applicable)*	1	2	3	4	5

6.2. How often do you meet with other PCCLs*? Please tick*:

	Weekly	Monthly	Quarterly	Never	Other (*write in)*
Locally	☐	☐	☐	☐	☐ . . . . . .
At network level	☐	☐	☐	☐	☐ . . . . . .
In the Macmillan Region	☐	☐	☐	☐	☐ . . . . . .
Nationally	☐	☐	☐	☐	☐ . . . . . .

6.3. Have you received sufficient guidance to fulfil the following aspects of your role?
Please circle one number in each row or tick the box:

	Too little	More than enough	Not applicable

Baseline assessment 1	2	3	4	5		☐
Prevention/screening strategies	1	2	3	4	5	☐
Smoking strategies	1	2	3	4	5	☐
Healthy eating strategies	1	2	3	4	5	☐
Monitoring 2 week rule	1	2	3	4	5	☐
Early diagnosis	1	2	3	4	5	☐
Care pathway development	1	2	3	4	5	☐
Lung cancer pathway	1	2	3	4	5	☐
Palliative care	1	2	3	4	5	☐
Commissioning at PCO level	1	2	3	4	5	☐
Commissioning at network level	1	2	3	4	5	☐
Establishing cancer datasets	1	2	3	4	5	☐
Implementing QA programme	1	2	3	4	5	☐
Feeding back local initiatives to Macmillan	1	2	3	4	5	☐

SECTION 7: Your views on the PCCL role

7.1. Have you seen the PCCL job description?

Yes☐ No☐

What did you think about it? *Please describe in one word:*

7.2. What do you regard as the THREE most important personal attributes needed by PCCLs?
Please write in:

7.3. In what ways, if any, has the PCCL role contributed to the improvement of patient's experiences of local services?
Please write in:

7.4. Has your role changed over time?

Yes ☐ No ☐

If yes, in what ways*? Please write in:*

7.5. Have any of the following skills improved since you became a PCCL?
Please circle one number in each row:

Not at all	Very considerably

Influencing	1	2	3	4	5
Negotiating	1	2	3	4	5
Assertiveness	1	2	3	4	5
Problem solving	1	2	3	4	5
Collaboration	1	2	3	4	5
Change management	1	2	3	4	5
Presentation skills	1	2	3	4	5
Business planning	1	2	3	4	5
Knowledge of cancer pathways	1	2	3	4	5
Managing workload	1	2	3	4	5
IT	1	2	3	4	5
Empathising with patients	1	2	3	4	5

7.6. Which of the above changes, if any, would you attribute to the training provided for you as PCCL? *Please write in:*

7.7. What impact, if any, do you expect the new GP contract to have on your activities as a PCCL? *Please write in:*

7.8. With hindsight, how do you feel about your decision to take up your PCCL post?
Please circle one number:

Very negative				Very positive
-2	-1	0	1	2

SECTION 8: Impact of PCCLs

8.1. Please reflect on the last working week. Write down your activities as a PCCL and the amount of time spent on each:

Activity	**Time**

8.2. Has being a PCCL had any impact on your own GP practice? *Please tick*:

	Yes	No
Not in a practice	☐	☐
Consulted by other GPs about PCCL activities	☐	☐
Resentment from other GPs	☐	☐
Used as a resource by the practice	☐	☐
Changed referral patterns	☐	☐
Difficulty in getting locum cover	☐	☐
Increased workload on days when in practice	☐	☐
Changed palliative care provision	☐	☐
Other *(specify)*	☐	☐

SECTION 9: Cancer specific Education and Training

Macmillan Support Programme:

9.1.(a) Are you aware of any of the following aspects of the Macmillan support programme? *Please tick:*

	Yes	No
Individual learning opportunities	☐	☐
Collective learning set events	☐	☐
Cancer network events/activities	☐	☐
Regional conferences	☐	☐
PCCL website	☐	☐
Support materials	☐	☐

9.1.(b) How often have you made use of any of the following aspects of the Macmillan Support Programme?

	Frequently	Occasionally	Never
Individual learning sets	☐	☐	☐
Collective learning set events	☐	☐	☐
Cancer network events/activities	☐	☐	☐

Regional conferences	☐	☐	☐
PCCL website	☐	☐	☐
Support materials	☐	☐	☐

9.2. Has the Macmillan Support Programme for PCCLs contributed to your (*Please circle one number in each row):*

	Not at all				A lot
Knowledge/skills	1	2	3	4	5
Confidence	1	2	3	4	5
Networking ability	1	2	3	4	5
Managerial competence	1	2	3	4	5

9.3. Which aspects of the Macmillan Support Programme have you found particularly useful? *Please write in:*

9.4. Have you identified any additional support or training needs that the Macmillan Support Programme could have helped with?
Please write in:

9.5. Have you ever used the support programme as a vehicle to feed back details of local initiatives to other PCCLs? *Please tick one box;*

Frequently ☐ Occasionally ☐ Never ☐

9.6.Have you made use of the personal development opportunities available to PCCLs in the last year?

Yes ☐ No ☐

If yes, how many times? . . . .

9.7. Have you undertaken any additional cancer education/management since taking up your PCCL role (additional to the Macmillan Support Programme)?

Yes ☐ No ☐

If, yes, please describe

SECTION 10: The future of the PCCL role

10.1. Do you think the post of PCCL should continue beyond 2004? *Please tick one box*

Yes ☐ No ☐ Don't know☐

If yes, how many sessions would be ideal? *Please tick one box:*

Same as now ☐
More than now ☐
Fewer than now ☐

10.2. Has your PCT made a decision on funding for the PCCL post after March 2004?

Please tick one box: Yes ☐ No ☐ Don't know ☐

If Yes, was the decision to:

fund at the current rate ☐
increase funding ☐
reduce funding ☐
withdraw funding ☐
Other *(please write in):* ☐

10.3. Can you suggest any changes to improve the effectiveness of the PCCL role in the future?

Please write in:

10.4. Please add any further comments about the PCCL role in the space below:

And finally….

Please will you provide us with some personal details?

Please tick the relevant boxes:

Are you	Male	☐
	Female	☐

How old are you? . . . . years

Is your practice	GMS	☐
	PMS	☐
	Not applicable	☐

Are you employed in your practice:

	Full time	☐
	Part time	☐
	Not applicable	☐

Thank you very much for taking the time to complete this questionnaire
Please return in the FREEPOST envelope provided to:-

Centre for Research in Primary Care
University of Leeds
71-75 Clarendon Road
Leeds
LS2 9PL

If you would like an electronic summary of the findings from this evaluation please tick the box ☐ and clearly write your email address below:

Appendix 2:

The PCT Managers' Questionnaire

EVALUATION OF
THE PRIMARY CARE CANCER LEADS (PCCL)
INITIATIVE IN ENGLAND

The views of PCT Chief Executives

This is your opportunity to tell us your views on the PCCL scheme.

This evaluation has been funded by the Department of Health and Macmillan Cancer Relief to help inform decisions about the future role of PCCLs

Please help us by taking about 15 minutes

to complete the questionnaire.

The information you provide will remain anonymous.

Individual and PCT names will not be attached to any report.

Please return this questionnaire by

Dr Brenda Leese	Professor Phil Heywood
Reader in Primary Care Research	Professor of Primary Care Development

Centre for Research in Primary Care
University of Leeds
71-75 Clarendon Road
Leeds LS2 9PL

Are you the Chief Executive of your PCT?

Yes ☐ No ☐

If No, please write your job title below:

. . . .

Please describe how your job provides you with knowledge of the PCCL role:

If your PCT does not currently have a PCCL in post, please still answer the relevant questions.

SECTION 1: Questions about your PCT

1.1. What is the population size covered by your PCT? . . . .

1.2. What is the total number of GMS and PMS practices in your PCT? . . . .

1.3. Approximately how many GPs are there in your PCT?
Number of GP principals ....
Number of GPs on the Supplementary list ....

1.4. How would you describe the geographical area in which your PCT is located*?*
Please tick one box

Mainly:	inner city	urban	suburban	rural	mixed	other (*please describe*)
	☐	☐	☐	☐	☐	☐

. . . .

1.5.What are the THREE current main strategic objectives of your PCT?
Please write in:

1.

2.

3.

1.6. How has setting up a PCCL post influenced the strategic objectives of your PCT, if at all (whether or not the post is currently filled)?

Please write in:

1.7. On which issues in cancer care is your PCT focusing?

Please circle one number in each row to indicate priority:

	Low priority		High priority		Don't know	
Developing preventive services e.g. smoking cessation, healthy eating	1	2	3	4	5	☐
Screening	1	2	3	4	5	☐
Developing follow up services in primary care	1	2	3	4	5	☐
Building/improving communication between primary and secondary care	1	2	3	4	5	☐
Early diagnosis and referral (incl 2 week waiting target)	1	2	3	4	5	☐
Patient care pathways	1	2	3	4	5	☐
Supportive and palliative care		1	2	3	4	5
☐						
services						
Cancer services commissioning	1	2	3	4	5	☐
Working with Cancer Services Collaborative	1	2	3	4	5	☐
R&D	1	2	3	4	5	☐
Other *(Please specify)*	1	2	3	4	5	☐

SECTION 2: The PCCL in your PCT

2.1.Is the post of PCCL currently filled in your PCT? Yes ☐ No ☐

If yes, how long has your current PCCL been in post? . . . . months

If no, how long has the post been vacant? . . . .
months

2.2.How many PCCLs have been in post in your PCT since the scheme started in 2001? . . . . .

If you have no PCCL currently in post GO TO SECTION 3

2.3.For how many PCTs is your PCCL the cancer lead? *(include your PCT in the total)* . . . . .

2.4. What is her/his professional background? *Please tick one box:*

GP ☐
Nurse ☐
Other (*please specify*) ☐

. . . .

2.5.For how many hours a week is she/he employed in this role? . . . .

2.6. Do you consider that these hours are sufficient to achieve all that is required?

Yes ☐ No ☐

2.7. What administrative support does the PCT provide for the current PCCL?

			Hours/week
Secretarial	☐		....
Admin	☐		....
Other	☐	*(please specify)*	....

2.8. What are the key areas of work for the current PCCL in your PCT?

Please write in:

SECTION 3: How the role of PCCL has developed in your PCT

Even if there is no PCCL currently in post please answer Questions 3.1-3.3

3.1 (a) What do you consider to be the key achievements of your PCCL(s)?
Please write in:

(b) What do you consider to be the THREE main factors that have contributed to these achievements? *Please write in:*

3.2 (a) What has been attempted that has worked less well? *Please write in:*

(b) What were the THREE main barriers to achievement encountered by your PCCL(s)?

Please write in:

3.3. What are your PCT's priorities for the future with regard to your PCCL's tasks?
Please write in:

If you have no PCCL currently in post GO TO SECTION 4

3.4. Has your current PCCL focused on a specific aspect of cancer services since they took up their post?

Yes ☐ No ☐

If yes, which and why?

3.5. (a) Is your current PCCL:	Yes	No	Don't know
A member of the PEC	☐	☐	☐
A member of the PCT board	☐	☐	☐
(b) Does your current PCCL attend:			
PEC meetings	☐	☐	☐
PCT Board meetings	☐	☐	☐
Cancer Network meetings	☐	☐	☐
Other meetings in the PCT (*specify*)	☐	☐	☐

SECTION 4: Costs of the PCCL scheme

4.1. What is the latest annual allocation of funding to your PCT from the Department of Health for the PCCL role*?* £. . . . .

4.2. What is this used to support? *Please tick*

	Yes	No	Don't know
PCCL session(s)	☐	☐	☐
Support staff	☐	☐	☐
Office costs	☐	☐	☐
Other (*specify)*	☐	☐	

If no PCCL currently in post GO TO Q 4.4

4.3. Are you providing your current PCCL with any of the following as part of their role?:
Please tick

	Yes	No	Don't know

Office	☐	☐	☐
Computer	☐	☐	☐
Travel costs	☐	☐	☐
Training costs	☐	☐	☐

4.4. Can you estimate how much additional resource is provided annually by the PCT for the PCCL role?

(a) Funding *(excluding the annual allocation from DoH)* £. . . . .
. . .

(b) Support in kind *(e.g. 2 hours secretarial support/week)*

SECTION 5: Extent of collaboration

If no PCCL currently in post GO TO SECTION 6

5.1. Has your current PCCL contributed to the development of the Cancer Network?

	Yes	No	Don't know
By representing the PCT	☐	☐	☐
Developing service delivery plans	☐	☐	☐

5.2. Has your PCCL(s) contributed to raising the standard of cancer care in your PCT?

Yes ☐ No ☐

If yes, please explain how:

SECTION 6: The PCCL role

6.1. What do you regard as the important personal attributes needed by PCCLs?

Please write in:

6.2. Do you think patients will be aware of the existence of PCCLs?

Yes ☐ No ☐ Don't know☐

Please explain your response:

6.3. How has the PCCL role changed over time in your PCT?
Please write in:

If you have no PCCL currently in post GO TO SECTION 7

6.4. In what ways, if any, has your current PCCL contributed to the improvement of patient's experiences of local services?
Please write in:

SECTION 7: The future of the PCCL role

7.1. Do you think the post of PCCL should continue beyond 2004? *Please tick one box*

Yes ☐ No ☐ Don't know☐

If yes, how many sessions would be ideal? *Please tick one box.*

Same as now ☐
More than now ☐
Fewer than now ☐

7.2.a. Has your PCT made a decision on funding for the PCCL post after March 2004?

Please tick one box: Yes ☐ No ☐ Don't know ☐

If Yes, was the decision to:

fund at the current rate ☐
increase funding ☐
reduce funding ☐
withdraw funding ☐
Other *(please write in):* ☐

7.2.b If funding is to be withdrawn, please explain why this decision was made

7.3. What impact, if any, do you expect the new GP contract to have on the activities of the PCCL in your PCT? *Please write in:*

7.4. Can you suggest any changes to improve the effectiveness of the PCCL role in the future?

Please write in:

7.5. Please give your views on the scope of the PCCL role. *Please write in:*

7.6. Please add any further comments about the PCCL role in the space below:

Thank you very much for taking the time to complete this questionnaire

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Appendix 3:

The PCCL Job Description

Role of the Primary Care Cancer Lead Clinician

The Job Description, defined at the beginning of the project, describes the role as follows:

This is a strategic role.

The main purpose of which is to develop and streamline services for cancer patients within the PCO in collaboration with secondary and tertiary colleagues within the cancer network. Additionally, the post-holder will oversee quality assurance issues in collaboration with the clinical governance lead.

Managerial, secretarial and office support to be provided by the PCO.

TITLE: Primary Care Cancer Lead Clinician

RESPONSIBLE TO: PCO Board

REPORTING TO: PCO Board

PURPOSE

To provide strategic leadership within the PCO in line with the NHS cancer plan to develop services for cancer patients.

- Baseline assessment of current cancer and palliative care provision in PCO area.
- Prevention/screening strategy. The establishment and monitoring of a PCO wide strategy with emphasis of smoking strategy and healthy eating.
- Early diagnosis. Monitoring of “two week rule”. Access to investigations. PCO led early diagnosis services where appropriate to patients needs.

To contribute to the development of network service delivery plans in order to streamline patient care (using the “care pathway” approach).

- Development of primary care elements of site specific (e.g. lung cancer) patient care pathways, including palliative care.
- Participation in commissioning process at PCO and network level
- Maintain contact with Macmillan Cancer Relief and feed back details of local initiatives relating to cancer for collation and dissemination by the support team.

To contribute to network development and, where appropriate, to represent the PCO and primary care in the cancer network.

- Where appropriate, represent PCO and PCO grouping in such structures as the network establishes to manage a monitor the network (e.g. local, district or county level and board level).
- To raise the standards of cancer care within the PCO in collaboration with the clinical governance lead.
- Establish cancer datasets at practice level to reliably record the incidence and prevalence of the different cancers at practice level. This will inform both the audit process at practice level and the commissioning process at PCO/network levels. Other standards covering the entire patient journey from pre-diagnosis to palliative care can be incorporated as and when they become available.
- Implement QA programme (e.g. significant event audits, audit of use of guidelines etc.) In this a lot of the work already carried out by Macmillan GP Facilitators can be drawn on.

To ensure that services are responsive to the needs of people affected by cancer.

- The appointee will participate in meetings and training opportunities provided by Macmillan Cancer Relief and others. A minimum attendance at one network and one regional/national meeting a year is expected.

April 2001