Evaluation of Phase 1 of the One-to-One Support Implementation Project

Baseline Report

Macmillan Cancer Support

Evaluation of Phase 1 of the One-to-One Support Implementation Project Baseline Report for Macmillan Cancer Support

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Introduction

Macmillan Cancer Support is carrying out a major project that is piloting new ways of providing one-to-one support for people with cancer across the UK. The process will be split across two phases, with phase 1 (April 2012-May 2014) piloting the new approach in 16 sites across England, Wales, Scotland and Northern Ireland. With Macmillan committed to investing £300m over the next 7-10 years to support the NHS to create up to 3,400 additional one-to-one support posts across the UK, this is a substantial investment of resources, and represents a significant opportunity to:

- improve the quality of care, quality of life and experience for cancer patients, carers and family members
- identify new cost effective ways of improving quality of service, thereby using the initial investment to make the case for change

Phase 2 of the pilot has not yet been designed. Macmillan is strongly committed to developing this approach and type of support in the long term, and the findings and learning from the evaluation of phase 1 will be used to shape subsequent phases.

This report provides a baseline overview of the evaluation of phase 1 of the pilot, specifically:

- the background to the evaluation
- an overview of the project
- detail on what is happening at each pilot site
- an overview of what outcomes each project is likely to deliver
- emerging challenges
- factors to be considered for Phase 2

Cancer in the UK and the drivers for one-to-one support

The cancer story in the UK is changing. There are now two million people living with or beyond cancer in the UK, a figure that is increasing by 3.2% each year and a trend that, if it continues, could see 5.3 million people living with cancer in the UK by 2040[1]. There are more than 200 different types of cancer, but four tumour groups account for more than half of all new cases – breast, lung, bowel (colorectal) and prostate.

Cancer is the second largest cause of death in the UK behind cardiovascular disease. Substantial resources are already dedicated to cancer care in the UK (in 2008, this amounted to £5.13bn in direct costs to the NHS, with a further £0.36bn for hospice care[2]), and as our population ages, cancer treatment and care will absorb an increasing proportion of healthcare expenditure. These numbers say little of the devastating personal impact that living with cancer can have on individuals, their families and carers. New ways of working to reduce the incidence rate, increase awareness and early diagnosis, and reduce recurrence of cancer in patients could significantly reduce the number of lives cancer takes each year.

Advances in medicine and treatment have made 'the cancer story' much more complex. People now live longer with terminal cancers and have to cope with what that means in terms of quality of life, including lowered immunity to other long-term conditions and the long-term side effects that any cancer treatments may have. It is important to recognise that the emotional and physical effects of cancer do not cease just because a patient has completed their treatment.

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[1] Facts and Figures, Macmillan Cancer Support
[2] *The Cost of Cancer,* The Policy Exchange, 2010

Cancer has changed, and potential outcomes have increased exponentially, which makes it a complex disease to manage, treat and to provide adequate patient support for. Macmillan is committed to helping people living with or beyond cancer to access the care and support they need.

It is also important to note that the focus of cancer care has traditionally been on the treatment and prevention of cancer, with comparatively little focus placed on aftercare and survivorship. This is beginning to change through, for example, the:

- National Cancer Survivorship Initiative (England)
- Scottish Government's working group on survivorship
- Northern Ireland Assembly's Service Framework for Cancer Treatment and Care (which states that all patients should receive a holistic assessment at the end of each treatment episode and be actively involved in decision making on their aftercare arrangements)
- Welsh Government's Cancer Delivery Plan (which states that each health board should assign a named key worker to assess and record a care plan for everyone diagnosed with cancer)

Nurse-led support is therefore becoming increasingly important, particularly in terms of educating patients and providing the psychosocial support they need throughout their 'cancer journey'. No two patients are the same, and tailored support is imperative for improving the quality of life of the increasing number of people living with the consequences of cancer in the UK.

The recently published 2011/12 Cancer Patient Experience Survey includes a number of findings that further support the requirement for the introduction of support such as the One-to-One Support Implementation Project, for example:

- 70% of patients reported that their views were definitely taken into account when the team of doctors and nurses were discussing what treatment they should have – therefore 30% did not feel that their views had been taken into account
- only 52% of patients said that hospital staff gave them information about how to get any benefits they may be entitled to
- only 61% of patients reported that they were definitely given enough care and help from health and social services after leaving hospital
- 62% of patients reported that different people (e.g. GPs, hospital doctors/nurses, specialists and community nurses) treating and caring for them always worked well together to give them the best possible care
- only 24% of patients said they had been offered a health assessment and care plan

The expected rise in those diagnosed with or surviving cancer, combined with the severe restraints on resources within the current economic climate, provides a strong impetus to explore new models of care that deliver earlier intervention and diagnosis, improved access and more integrated and personalised services. This will deliver improved clinical outcomes and experience for patients and carers in a more cost effective way.

There is also substantial evidence[3] that one-to-one support can significantly improve access to, and quality of, care for cancer patients, as well as delivering improvements in patient outcomes. Recent estimates by Frontier Economics[4] put the additional annual cost of providing one-to-one support to all cancer patients at around £59.7m (central estimate), which would be offset by the annual gross benefit to the NHS of £88.8m (central estimate) as well as those patient level benefits, reaped due to the improved support offered to them, that have not been quantified.

Cancer care policy in the UK – does the One-to-One Support Project fit?

The One-to-One Support Implementation Project aligns strongly with – and will contribute to the implementation of – healthcare policy both across the UK and in each of the four home nations. Specifically:

- all four home nations have cancer-specific plans
- all four home nations also promote the following elements of care which fit well with one-to-one support:
    - a focus on early detection and awareness
    - improved information for GPs and the public
    - access to greater levels of nurse-led support

The only area of potential concern in relation to the ability of policy frameworks in the UK to support this type of activity is in Wales, where there is a lack of policy infrastructure to support or promote survivorship (the Cancer Plan only briefly mentions survivorship). The result is that survivorship is not a KPI/target (all the KPIs relating to cancer in Wales relate to reducing waiting times). Although this is unlikely to directly influence the delivery of the pilot as they have worked hard to secure buy-in at executive board level, it may have a negative influence on sustainability of the roles.

While the One-to-One Support Implementation Project is consistent with cancer care policy in the UK, sustainability of the posts may still prove to be a challenge in the medium to long term given the significant pressure on resources within the UK's health and social care systems. The first step to addressing this is to ensure that the impact delivered by this model is not only robustly evidenced, but robustly evidenced from the perspective of each key stakeholder group (e.g. central and devolved government, patients, clinicians in both primary and secondary care, commissioners) – in short, proving that one-to-one support works and delivers better outcomes and impact in a cost effective way. This will enable Macmillan to continue to work to influence policy across the UK to ensure that this approach, if successful, is built into future models of health and social care (and workforce planning).

The cohort

There are 16 Macmillan One-to-One Support pilot sites across the UK, 15 of whom will be included within this evaluation (one site at UCLH is being evaluated separately as part of a wider initiative). The pilot sites provide good coverage across the UK, with ten in England, two in Wales, two in Northern Ireland and one in Scotland.

The fifteen pilot sites therefore offer an excellent opportunity to evaluate the impact of introducing the One-to-One Support roles into a range of healthcare settings and policy contexts, and evidence the extent to which they deliver the anticipated outcomes and impacts.

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[3] See, for example: 'A Patient's Journey: Living with Breast Cancer', Brookes (2006); 'Clinical Nurse Specialists: Adding Value to Care' RCN (2010); 'Assessing the Value of a Cancer Clinical Nurse Specialist on Patient Outcomes', Sullivan and Elliot (2007); 'The impact of the Clinical Nurse Specialist within a Palliative Care Team in an acute hospital setting, on cancer patients symptoms and insight' Jack, Oldham, Williams, Hillier (2003)
[4] One-to-one support for cancer patients, Frontier Economics, 2010

It is clear that the proposed approach and aims and objectives highlighted by the sites align strongly with Macmillan's anticipated outcomes for the pilot programme as they are defined in the programme logic model. While it is too early to tell if some of these outcomes will be met (for example the extent to which the roles are accepted by peers and seen as credible and as complimentary to existing roles), the early indicators are positive, specifically in relation to:

- proposing to make changes to the care pathway that provide more joined up services to better meet the needs of people living with and beyond cancer
- maintaining a focus on improving the quality of care and patient experience
- improving clinical outcomes
- improving productivity

Strong stakeholder support

There is strong stakeholder support for the pilot, and stakeholders are extremely enthusiastic about the potential of the pilot to deliver a wide range of outcomes and impacts, both within the health and social care systems and for patients. This level of support provides a strong foundation for the pilot, and significant levels of expertise and influence to tackle any challenges that emerge as it progresses.

This level of support also brings a degree of pressure for Macmillan and the pilots themselves. It will therefore be important to manage expectations at all levels across the lifetime of the pilot, ensuring they are in line with the project's core aims and objectives, and what can be delivered by 64 posts across 15 pilot sites.

Early themes emerging from the pilot sites

There are a number of themes that emerged from our early consultations with the pilot sites and may have an impact on both the short and long-term performance of the One-to-One Support mechanism particularly in relation to:

- stakeholder engagement key for success: the success of the pilots will be strongly influenced by the ability of pilot leads and postholders to secure the support of key influencers – both within their own organisation and across the wider healthcare system. Buy-in from clinical staff will be crucial – particularly in relation to primary care professionals who will have a significant impact on the pilots, but have traditionally been less involved with cancer treatment

- recruitment: the quality of applications received by the pilot posts to date has been mixed. While some report that they were extremely pleased with the volume and quality of applications they have received, others have experienced difficulty in recruiting the calibre of staff with the skills they require. Particular barriers include the fixed term nature of the posts (with potential candidates particularly concerned about what posts would be available for them at the end of the period, given the current uncertainty within the NHS), or local HR processes that were inhibiting the recruitment process. There is also an association amongst many applicants of the Macmillan brand having strong links to palliative care, with the result that candidates who present for interview have the wrong idea about the aims of these posts. Where this has occurred, sites have re-advertised the posts with a strong emphasis on highlighting that these posts will provide support to people living with or beyond cancer.

Some of this could be mitigated in the future by ensuring that the sites are very explicit and clear in the recruitment advertisement that the posts are not palliative – an area where Macmillan could potentially help by highlighting this as an issue for any future sites and that any future advertisement includes some carefully designed text that describes what the posts are. It will be important for the evaluation to continue to track the quality of applicant that is recruited to these posts as the recruitment process continues, and factor this into our analysis of how the pilots perform

- training and education: the requirement for a strong training and induction process has been highlighted across the sites. While specific elements of the training and induction processes vary by site, all are consistent in terms of focusing on enabling the postholders to build strong relationships with key local stakeholders. Some pilots are planning to supplement this with Macmillan support for the postholders – for example the introduction to cancer course – and Macmillan should consider focusing support to the sites on highlighting the range of development support they can offer to maximise the impact of the new roles

- anticipated outcomes and impact: pilot leads' articulation of the expected outcomes from, and impact of, their projects maps very well to the logic model for the programme. A key overriding theme was an expectation that the new model will deliver seamless and holistic care. Specifically:
  - in relation to patient experience and outcomes, there was strong coverage across the pilots in terms of expected outcomes on:
    - improved satisfaction
    - single point of contact
    - better information
    - better signposting
    - proactive patient management
    - less isolation
    - support for self-management
  - in relation to clinical outcomes:
    - improved quality of life
    - to a lesser extent, better awareness of the signs of recurrence
    - improving knowledge amongst primary care professionals
    - providing more services that better meet patients' needs through primary care in community settings
  - in relation to improved productivity:
    - more cost-effective skill mixing, freeing up CNS time to focus on more complex cases
    - reducing unnecessary admissions
    - reducing unnecessary GP visits
    - reducing unnecessary outpatient follow-ups

Each of these factors will be closely monitored throughout the evaluation, as we work closely with the pilot sites to quantify and evidence the impact that one-to-one support delivers.

1   Introduction

Macmillan Cancer Support is carrying out a major project that is piloting new ways of providing one-to-one support for people with cancer across the UK. The process will be split across two phases, with phase 1 (April 2012-May2014) piloting the new approach in 16 sites across England, Wales, Scotland and Northern Ireland. With Macmillan committed to investing £300m over the next 7-10 years to support the NHS to create up to 3,400 additional one-to-one support posts across the UK, this is a substantial investment of resources, and represents a significant opportunity to:

- improve the quality of care, quality of life and experience for cancer patients, carers and family members
- identify new cost effective ways of improving quality of service, thereby using the initial investment to make the case for change

Phase 2 of the pilot has not yet been designed. Macmillan is strongly committed to developing this approach and type of support in the long term, and the findings and learning from the evaluation of phase 1 will be used to shape subsequent phases.

One-to-one support for cancer patients might best be understood as a service that supports the patient across the whole cancer pathway, based on the intensity and nature of patients' needs, in order to improve quality of care and patient experience and outcomes in a more cost effective way. Phase 1 of the project involves piloting the introduction of four new roles across health and social care settings: Macmillan Cancer Support Worker; Macmillan Nurse Primary Care; Macmillan Nurse Community Care; and Macmillan Complex Case Manager.

Macmillan has commissioned a consortium led by Frontline, in partnership with the University of West of England at Bristol and BresMed Health Solutions, to evaluate phase one of the pilot. This baseline report presents the findings from the initial research undertaken by the evaluators, including the outputs from:

- a literature and baseline data review
- initial consultations with each of the pilot sites
- consultations with key strategic stakeholders
- initial baseline data collection from the sites

The purpose of this report is to provide an overview of this research, and specifically:

- the background to the evaluation
- an overview of the project
- detail on what is happening at each pilot site
- an overview of what outcomes each project is likely to deliver
- emerging challenges
- factors to be considered for Phase 2

2   Methodology

This section summarises the methodology for the evaluation as a whole and contains information about the data sources upon which this baseline report is based.

2.1   Evaluation aims and objectives

There are two main aims for this evaluation:

- to carry out an **impact and process evaluation** of the four new roles that provide one-to-one support to people with cancer
- to undertake **economic analysis to assess cost-effectiveness** of the new roles compared with current practice

The specific objectives for the evaluation are to:

- provide regular findings that help Macmillan to test whether the roles are fit for purpose (and provide the right model of care), and help us to achieve better outcomes for people with cancer
- draw out evidence and lessons learned on what works (and what doesn't work), for whom, why and in what circumstances – in order to continually shape the development of the project and inform the second phase
- undertake a robust economic analysis to show whether the new roles deliver value for money – looking at the costs of introducing the roles against the achieved benefits
- take an active role in promoting peer learning across the pilot sites and in sharing the findings and key lessons learned to the pilot sites on a regular basis, including through the design and facilitation of a series of learn and share events

The findings from the evaluation will be used by Macmillan and partner organisations to inform the future development and roll out of these posts across the UK.

2.2   Evaluation design

The project is being conducted following the principles of realist evaluation (Pawson and Tilley 1997). The focus is therefore on collecting data which can illuminate what works for whom, in which circumstance and why. The introduction of the new roles has built on robust research to identify current gaps in provision for people living with cancer, and what the anticipated outcomes and impact of introducing this type of support would be. The evaluation has been designed around this 'theory of change' approach, seeking to specifically measure if and to what extent the anticipated outputs, outcomes and impacts are realised (Appendix 3 presents the logic model for this evaluation, detailing the anticipated inputs, activities, outputs, outcomes and impacts this pilot will deliver).

Both quantitative and qualitative data will be collected from NHS staff and from other individuals by means of on-line survey and/or individual interview, conducted either by telephone or face-to-face. All external and internal stakeholders (see below), all NHS pilot/education leads (whichever role is more relevant) in the 15 participating NHS sites, and all holders of the new Macmillan posts (postholders) will be asked to participate in the interviews and/or survey. These will include sites in all four UK countries.

Data collection at the case study sites will focus on gaining a more in-depth understanding of the processes involved in implementing the new posts, including contextual factors, partnership working and any consequences, unintended or otherwise.

This will entail interviewing appropriate staff and external collaborators, e.g. GPs. Data collection is planned as follows:

1. External stakeholders– one individual interview (telephone or face-to face) with each person. All these individuals have some specific experience in this area, and have been involved in the development of the One-to-One Support Implementation Project (see 4 below). These interviews will be conducted at the beginning of the project to collect background and baseline data.

2. Internal stakeholders – individual interview (telephone or face-to face) with each person. All these individuals are Macmillan employees and have been involved in the development of the One-to-One Support Implementation Project. These interviews will be conducted at the beginning of the project to collect background and baseline data.

3. NHS pilot/education leads– four individual telephone interviews with each person. Interviews will be conducted at the beginning of the project to collect background and baseline data; twice during the project to collect data about the progress of the pilot; and at the end of the project, to collect data about the overall progress and success or otherwise of the pilot as a whole.

Postholders – on-line survey, to be completed once at the beginning of the project, to collect background and baseline data. This will be supplemented by two individual telephone interviews with each postholder. These will be held approximately six months into the project, and again towards the end of the project, to collect data about the postholder's experiences in the new role.

4. Study site visits– three individual interviews will be held with the pilot/education lead and all postholders in each site. These interviews will be held near the beginning of the pilot, approximately midway through the evaluation, and towards its end. An individual interview will also be held with external collaborators in each site, e.g. GP, consultant oncologist, dietician. All these interviews will be held face-to-face, unless it is only possible to conduct them by telephone.

5. Patient survey – we will recruit up to 300 patients from each of the participating NHS organisations to the study. These patients will be those who have been referred, and whose care is being managed, by an individual in one of the new support roles. Patients will only be recruited to the study if aged 18 or older. The survey will be supplemented by qualitative data on patients' experience obtained through a series of patients and carers focus groups, to explore findings arising from the survey in greater depth.

All patient participants will be asked to complete a survey in Autumn 2012 which will comprise of two quality of life measures and a questionnaire about their experience of cancer care (including support issues).

2.3   Baseline data sources

This baseline report is based on data from the following components of the methodology:

- a literature and baseline data review
- consultations with key strategic stakeholders
- initial consultations with each of the pilot sites
- initial baseline data collection from the sites

The **literature and baseline data review** compromises a search of relevant research papers, articles, documents and data from UK and international sources. It summarises the case for change in the survivorship pathway for people affected by cancer. It contrasts the differing policy environments across the four home nations within which this intervention is being made. It identifies the evidence base for one-to-one support in similar and comparable service contexts.

We held consultations with key strategic stakeholders, interviewing 17 people from the following organisations/backgrounds:

- Macmillan
- user representatives
- representatives from the Department of Health
- senior stakeholders from the devolved nations
- Nurse Directors from Cancer Networks
- representative from Social Care Institute for Excellence

We held **initial consultations with each of the pilot sites**, speaking with the project team leads to provide detailed insight into the aims and objectives of the projects, the contexts into which they are being placed, the baseline position, and their experiences and learning so far.

The **initial baseline data collection from the sites** comprises data relating to existing activity levels and outcomes within the health systems into which the new posts are being placed. Data was requested relating to the time period of one complete year prior to the introduction of the new posts, and covers areas such as:

- **inpatient data** – admissions and length of stay
- **outpatient data** – new and follow up appointments
- **primary care data** – appointments with GPs and practice nurses
- **community services data** – appointments with community nursing staff

We are continuing to work in partnership with each site to explore and agree what data will be collected throughout the evaluation.

3   The Macmillan One-to-One Support Implementation Project

Macmillan's recently published Cancer Workforce Development Strategy (2012-15)[5] highlights the importance of providing joined up care using multidisciplinary and skill-mixed professional staff to serve cancer care in future. Improvements in cancer survival mean that all healthcare staff may come into contact with survivors and there is recognition and commitment to bringing together specialist and general care to deliver the best service for patients.

> *"It is a myth that people who are cured of cancer are therefore well. Lots of people survive cancer but at least a quarter have unmet needs from their cancer and treatment. New cancer and treatment related illnesses emerge months, years, or decades later. Survivors experience more chronic illness and need to be made aware that lifestyle changes are important". (Macmillan, 2011)*

The cancer workforce that will be required in future is set to grow, along with the improving rates in cancer survival. There is also a focus that shifts away from traditional acute cancer care to a more tailored, home-centred approach to care that joins up services and gives patients what they want – in line with the 'no decision about me without me' as promoted by the Department of Health. Macmillan is also committed to leading initiatives to retain experienced staff specialising in cancer so that the supply of and demand for cancer professionals align.

It has become clear that the requirement for care is about the right person with the right skills and knowledge to meet individual needs at the right time for them. One-to-one support focuses on delivering patient centred care, and is best understood as a service delivered by an integrated team comprising of specialists (e.g. Clinical Nurse Specialists and AHPs – Levels 6 and 7) and generalists (e.g. Support Worker - Level 4, District and Practice Nurses – Levels 6 and 7) who support the patient across the whole cancer pathway, based on the intensity and nature of the needs of patients and care will be tailored to meet those needs.

Macmillan are developing a variety of ways to help bridge the gap to provide all people affected by cancer with the one-to-one support they need, which will include some direct funding for additional professionals, some investment in whole care pathway redesign and piloting new healthcare workforce roles.

Currently not all people affected by cancer get access to a CNS or a key worker, which we know makes a difference to patient reported outcomes and experience (see chapter four)). We also know that current models of follow-up are unsustainable if the number of people affected by cancer is going to double. Macmillan has been working across the UK to develop solutions to these issues. Redesigning the cancer care pathway, re-profiling and integrating the workforce and how it supports the cancer care pathway and developing new models of aftercare are seen as some of the solutions. The emerging models for aftercare (National Cancer Survivorship Initiative) demonstrate that care needs should be assessed at key transition points along the care pathway and a plan of care developed to reflect risk stratification into one of 3 levels of care:

- <u>supported self-management</u> – where patients are given the information about self-management support programmes or other types of available support, the signs and symptoms to look out for and who to contact if they notice any, what scheduled tests they may need such as annual mammograms, and how they get in touch with professionals if they have any concerns

- <u>shared care</u> – where patients continue to have face to face, phone or email contact with professionals as part of continuing follow up
- <u>complex case management</u> – where patients are given intensive support to manage their cancer and/or other conditions

Cancer survivors may move between these different options according to how their cancer and its treatment progresses and whether they are more able to manage their disease, or whether they need more help. The proportion of people in each option will vary depending on tumour type. Risk stratification means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease, (what type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short term and long term) and the person (whether they have other illnesses or conditions, and how much support that they feel they need).

Macmillan has developed 4 new healthcare roles, which are being piloted as part of the One-to-One Support implementation project which will support the 3 levels of risk stratified care and are the subject of this evaluation. The roles are: Macmillan Nurse Primary Care, Macmillan Nurse Community Care, Macmillan Complex Care Manager, Macmillan Support Worker. We see these new roles supporting the 3 levels of aftercare as outlined in the diagram below:

Figure 13: National Cancer Survivorship Risk Stratification Model of Aftercare
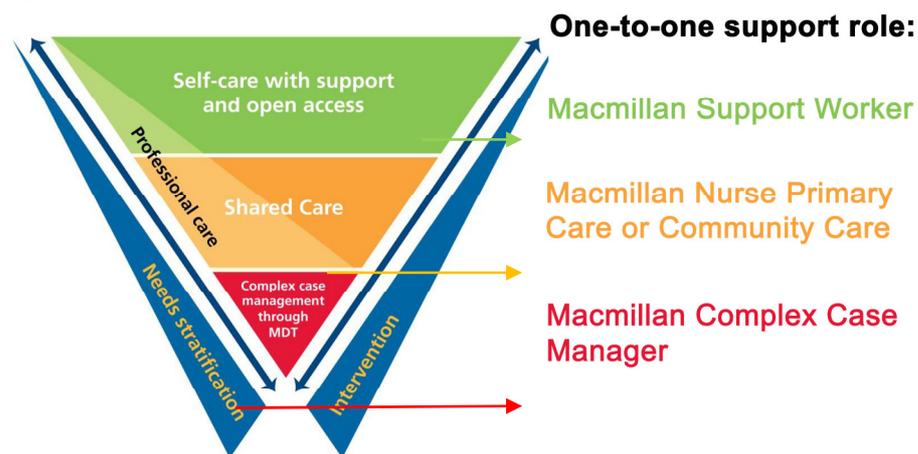
Below is a brief summary of each of the roles:

Macmillan Support Worker:

- supervised by registered practitioner within an existing team in health or social care
- coordinate care by providing a single point of access into the service, helping people to navigate the system
- coordinate care for people with non-complex care needs
- coordinate education and support for people with non-complex care needs

Macmillan Nurse Primary Care or Community Care:

- existing Practice Nurse or District Nurse
- released sessionally to provide care and support for people risk stratified into Level 2 – Shared Care.
- share care – between acute and primary/community care and between the professional and patient.
- use existing skills with LTC and enhance for cancer
- proactively manage the Treatment Summary and Cancer Care Review and support the transition to living beyond cancer.
- facilitate education and support of patients/carers and primary or community healthcare teams.
- support local cancer service redesign

Macmillan Complex Case Manager:

- existing case manager/modern matron in LTC
- released sessionally to manage a complex caseload
- proactive case-management of people living in the community with cancer and multiple co-morbidities, using LTC skills and liaising with Cancer MDT
- facilitate education and support of patients/carers and community healthcare teams
- support and influence local cancer service redesign
- support and influence commissioning of local cancer services

These 4 roles are being piloted as part of the One-to-One Support Implementation Project in 16 locations across the UK. The roles have been designed to facilitate workforce and succession planning for cancer care in the UK and show Macmillan's commitment to innovating and leading the way to ensure that the aspirations for cancer care are not under resourced. Pilot project details are provided in the section 10.

15 of the pilots are included in this evaluation. The other pilot is being delivered by University College London Hospitals and is being evaluated as part of a wider redesign programme.

4   Cancer in the UK

Key points summary

- the cancer story is changing:
  - Two million people are currently living with or beyond cancer in the UK
  - if current trends continue, four million people could be living with cancer in the UK by 2030;
  - improvements in survival rates are moving cancer from a 'terminal disease' to a 'chronic life threatening illness'
  - substantial NHS resources are already dedicated to cancer care – the level of increase in resource is unlikely to increase in proportion to the level of increase in demand, with the result that systems in their current form will be inadequate
- cancer care is one of the most complex care pathways in the NHS, and new treatments can result in cancer becoming a more complex illness to manage
- patients report facing significant challenges in accessing follow up care. The most common problems in accessing this type of support are attributed to a lack of:
  - coordination
  - local provision
  - integrated and holistic care
  - specialised services, either locally or in some instances nationally
- therefore new models of healthcare are needed to meet the requirements of people living with and surviving cancer in a cost effective way

4.1   Introduction – cancer in the UK

The cancer story in the UK is changing. There are now two million people living with or beyond cancer in the UK, a figure that is increasing by 3.2% each year and a trend that if it continues, could see 5.3 million people living with cancer in the UK by 2040[6]. There are more than 200 different types of cancer, but four tumour groups account for more than half of all new cases – breast, lung, bowel (colorectal) and prostate.

Of those diagnosed with cancer, approximately one quarter will die from it[7]. It is the second largest cause of death in the UK behind cardiovascular disease which makes it a massive issue for the health and wellbeing of the UK as well as a phenomenal drain on the NHS and care services. With substantial resources already dedicated to cancer care in the UK (in 2008, this amounted to £5.13bn in direct costs to the NHS, with a further £0.36bn for hospice care[8]), new ways of working to reduce the incidence rate, increase awareness and early diagnosis, and reduce recurrence of cancer in patients could significantly reduce the number of lives cancer takes each year. As our population ages, cancer treatment and care will absorb an increasing proportion of healthcare expenditure. These numbers say little of the devastating personal impact that living with cancer can have on individuals, their families and carers.

4.2   Cancer in the UK – comparing the home nations

The latest statistics illustrate the differences across the UK and give an idea of the future levels of cancer prevalence across the 4 nations. Prevalence figures are based on the assumption that the number of people living with cancer continues to grow at an annual rate of 3.2%.

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[6] Facts and Figures, Macmillan Cancer Support
[7] www.cancerrecovery.org.uk
[8] *The Cost of Cancer,* The Policy Exchange, 2010
MA0707-00

Figure 4: Estimated number of people living with cancer: by nation at the end of 2010, 2020 and 2030

	2010	2020	2030
England	1,800,000	2,400,000	3,300,000
Scotland	190,000	260,000	360,000
Wales	120,000	160,000	220,000
Northern Ireland	55,000	75,000	100,000
United Kingdom	**2,000,000**	**3,000,000**	**4,000,000**

Macmillan Cancer Support, 2012[9]

Of those living with cancer, the majority are over the age of 65 with one in eight of this age group having had a cancer diagnosis. The table below also splits statistics by gender, showing that there are a higher proportion of females living with cancer (that is known about and has been diagnosed).

Figure 5: Proportion of UK population living with cancer: by gender and age (2008)

	Males	Females
0-44	0.4%	0.5%
45-64	2.6%	5%
65+	13.1%	12.7%
Total – all ages	**2.7%**	**3.8%**

Macmillan Cancer Support, 2012[10]

Analysing cancer incidence statistics per day and month for each nation, as shown below, emphasises the sheer number of people diagnosed with cancer in the UK and demonstrates how common diagnoses are now.

Figure 6: Number of new cases of cancer: by nation (2009)

	Every day	Every month	Every year
England	750	22,100	265,000
Scotland	80	2,500	30,000
Wales	50	1,500	18,000
Northern Ireland	20	650	8,000
United Kingdom	**900**	**26,650**	**320,000**

Macmillan Cancer Support, 2012[11]

Significant improvements in cancer care in the UK have led to an almost 20% reduction in mortality rates since 1995, but the personal, social and economic costs of cancer remain substantial. Recent research estimates that 1.3 million people in the EU will die from cancer in 2012[12] which is actually a reduction in the rate of cancer mortality for the EU of 7% for women and 10% for men. The improvements in cancer survival rates have reclassified cancer from a 'terminal disease' to a 'chronic life-threatening illness' (Welsh Assembly Government, 2012). Looking back, cancer has been viewed as being something you either died from or were cured of.

The lowest survival rates are associated with pancreatic, stomach, oesophagus, brain and lung cancers. The highest incidences of death are associated with lung, colorectal, breast and prostate cancers across all nations in the UK.

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[9] Source: Macmillan Cancer Support estimates based on Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547. Crude estimates made for the end of 2010, 2020 and 2030 assuming that the current rate of increase (3.2%) continues. (Estimates assume any increase is consistent across each nation and remains unchanged over the 20 years, as such they are indicative only, are not statistically reliable and could change as more information becomes available).

[10] Ibid.

[11] Ibid

[12] Cancer mortality drops in Europe; article published by www.medicalnewstoday.com ; 29th February 2012

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Figure 7: Number of people who die from cancer: by nation (2010)

	Every day	Every month	Every year
England	350	10,850	130,000
Scotland	40	1,250	15,000
Wales	20	650	8,000
Northern Ireland	10	350	4,000
United Kingdom	**420**	**13,000**	**157,000**

Macmillan Cancer Support, 2012[13]

The statistics highlight the fact that there has been a significant increase in the number of people living with or beyond cancer and that this is estimated to double by 2030. Over the next 8 years, estimates show that around 3 million people in the United Kingdom will fall into this category – that equates to about 1 in every 22 people (based on ONS population estimates for 2020).

With so many of us affected by cancer – and the knock on effect this will have on families, carers, and employers – we need to have adequate support provision in place that takes some level of burden away from GP practices and in-patient hospital services, while at the same time reaching more people with very personal support requirements. This is where one-to-one support provided through CNSs and multidisciplinary teams including Macmillan nursing staff can play a crucial role. Before this is examined in detail, it is important to review the current UK policies which may or may not facilitate this approach.

4.3 Cancer care in the UK

Advances in medicine and treatment have made 'the cancer story' much more complex. People now live longer with terminal cancers and have to cope with what that means in terms of quality of life, including lowered immunity to other long-term conditions and the long-term side effects that any cancer treatments may have. It is important to recognise that the emotional and physical effects of cancer do not cease just because a patient has completed their treatment. Cancer has changed and potential outcomes have increased exponentially, which makes it a complex disease to manage, treat and to provide adequate patient support for. Macmillan is committed to helping people living with or beyond cancer to access the care and support they need, regardless of whether they believe they 'had' or 'have' cancer[14].

It is also important to note that the focus of cancer care has traditionally been on the treatment and prevention of cancer, with comparatively little focus placed on aftercare and survivorship. This is beginning to change, for example the:

- National Cancer Survivorship Initiative (England)
- Scottish Government's working group on survivorship
- Northern Ireland Assembly's Service Framework for Cancer Treatment and Care (which states that all patients should receive a holistic assessment at the end of each treatment episode and be actively involved in decision making on their aftercare arrangements)
- Welsh Government's Cancer Delivery Plan (which states that each health board should assign a named key worker to assess and record a care plan for everyone diagnosed with cancer)

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[13] Source: Macmillan Cancer Support estimates based on Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547. Crude estimates made for the end of 2010, 2020 and 2030 assuming that the current rate of increase (3.2%) continues. (Estimates assume any increase is consistent across each nation and remains unchanged over the 20 years, as such they are indicative only, are not statistically reliable and could change as more information becomes available).

[14] Two Million Reasons, Ciaran Devane, Macmillan Cancer Support, 2008

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4.4 The current cancer patient experience

Recent evidence from the National Audit Office (2005) and the Picker Institute (2009) highlights the challenges patients experience in accessing follow up care, with only half of patients in some cancer groups benefiting from such support. Those who report having the 'best' access to follow up care, often describe 'working hard' to get it. The most common problems in accessing this support are attributed to a lack of[15]:

- co-ordination
- local provision
- integrated and holistic care
- specialised services, either locally, or in some cases nationally

Research has been carried out across all cancers and for specific tumour sites (mainly breast, prostate and colorectal) to try to understand the impact of aftercare on the patient experience and improvements in outcomes. Considerably improved survival rates in cancer have put massive pressure on clinical budgets and traditional means of 'aftercare' cannot be sustained by the NHS. These more traditional measures have tended to lack adequate psychosocial support and patients have felt isolated and 'apart' from professional assistance. There is now a trend towards nurse-led and patient-initiated follow-up which gives patients more influence over their own aftercare.

> *"In the main, there is high satisfaction with patient led follow up by low to moderate risk breast cancer survivors, as long as they are confident to assess their own symptoms, have a clear indication of their future risk profile, receive annual mammographic surveillance and are provided with a safe, reliable and quick route back to specialist care if needed". (Davies and Batehup, 2011[16])*

The changes in survivorship and number of people living with terminal cancer has heightened the fear among survivors of cancer recurrence and the debilitating psychological effects cancer can have on people. The provision of cancer services needs to change in line with the changed perception of cancer and the changes in how cancer impacts those affected by it.

Nurse-led support has become increasingly important, particularly in terms of educating patients and providing the psychosocial support they need throughout their 'cancer journey'. No two patients are the same and tailored support is imperative for improving the quality of life of the increasing number of people living with the consequences of cancer in the UK. This type of support has already proven valuable in cancer patient follow-up care:

> *"[Our] findings…emphasise the important role colorectal nurse specialists play in providing information and support to patients following treatment. Future strategies aimed at providing follow-up care for colorectal cancer patients should draw on their knowledge and skills. Providing continuity of care may prevent minor physical and psychological problems escalating into long term chronic conditions that would be costly to the NHS". (An exploratory study of the follow-up care needs of patients treated for colorectal cancer, Beaver et al, 2010).*

The recently published 2011/12 Cancer Patient Experience Survey includes a number of findings that support the requirement for the introduction of support such as the One-to-One Support Implementation Project, for example:

- 70% of patients reported that their views were definitely taken into account when the team of doctors and nurses were discussing what treatment they should have – therefore 30% did not feel that their views had been taken into account

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[15] Cancer Follow Up Care: the views of patients and carers, Picker Institute, 2008
[16] Towards a personalised approach to aftercare: a review of cancer follow-up in the UK
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- only 52% of patients said that hospital staff gave them information about how to get any benefits they may be entitled to
- only 61% of patients reported that they were definitely given enough care and help from health and social services after leaving hospital
- 62% of patients reported that different people (e.g. GPs, hospital doctors/nurses, specialists and community nurses) treating and caring for them always worked well together to given them the best possible care
- only 24% of patients said they had been offered a health assessment and care plan

The 2011/12 survey also confirmed the importance identified in the 2010 survey of patients having the name of a Clinical Nurse Specialist – with both surveys finding that on almost all questions, patients with a CNS gave more positive scores than patients without a CNS. It is also worth noting that the scale of these differences is very substantial and has been maintained over the two surveys. The proportion of patients reporting that they had access to a CNS rose slightly from 88% in 2010 to 90% amongst those starting treatment in the last year.

4.5   The case for one-to-one support

The expected rise in those diagnosed with or surviving cancer, combined with the severe restraints on resources within the current economic climate, provides a strong impetus to explore new models of care that deliver earlier intervention and diagnosis, improved access and more integrated and personalised services. This will deliver improved clinical outcomes and experience for patients and carers in a more cost effective way.

> "[Cancer follow up in the UK] highlights a shift towards patient empowerment via individualised and group education programmes aimed at increasing survivors' ability to better manage their condition and the effects of treatment allowing for self-referral or rapid access to health services when needed. The focus is more on meeting individual care needs as opposed to the notion of 'one size fits all'. The challenge will be achieving this in a cost effective way that is either equally effective, or more so, than traditional clinical models of aftercare". (Davies and Batehup, 2011)

Meeting the care and support needs of this growing cohort of cancer survivors may be resource intensive, but the effectiveness of offering one-to-one support bolsters the ethos of care reform by giving patients greater control over their support options and access to information.

There is substantial evidence[17] that one-to-one support can significantly improve access to, and quality of, care for cancer patients, as well as delivering improvements in patient outcomes. Recent estimates by Frontier Economics[18] put the additional annual cost of providing one-to-one support to all cancer patients at around £59.7m (central estimate), which would be offset by the annual gross benefit to the NHS of £88.8m (central estimate) as well as those patient level benefits, reaped due to the improved support offered to them, that have not been quantified.

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[17] See, for example: 'A Patient's Journey: Living with Breast Cancer', Brookes (2006); 'Clinical Nurse Specialists: Adding Value to Care' RCN (2010); 'Assessing the Value of a Cancer Clinical Nurse Specialist on Patient Outcomes', Sullivan and Elliot (2007); 'The impact of the Clinical Nurse Specialist within a Palliative Care Team in an acute hospital setting, on cancer patients symptoms and insight' Jack, Oldham, Williams, Hillier (2003)

[18] One-to-one support for cancer patients, Frontier Economics, 2010

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5   Cancer Policy in the UK

Key points summary

- there is significant scope for improving survival rates for cancer in the UK: for example, if survival rates in England were to improve to match the top performers in Europe, around 10,000 lives could be saved each year
- currently, not all people affected by cancer have access to a CNS or a key worker
- there is a policy drive across all four home nations to encourage the facilitation of greater levels of self-management
- all four home nations have cancer specific plans. Although the plans for England and Scotland have been viewed as being more comprehensive[19], the recent publication of the *Cancer Services Framework* in Northern Ireland and *Cancer Delivery Plan* in Wales have moved to redress this
- all four home national also all promote the following elements of care which fit well with the concept of one-to-one support:
    - a focus on early detection and awareness
    - improved information for GPs and the public
    - access to greater levels of nurse led support
- there are a number of UK wide barriers that make providing effective cancer care and support very challenging: one-to-one support offers significant potential to help address and overcome these
- the National Cancer Survivorship Initiative highlights as good practice that care needs of cancer patients should be assessed at key transition points across the pathway, and a plan of care adopted to reflect the resulting risk stratification based around:
    - supported self-management
    - shared care
    - complex case management

This section examines the policy direction of the UK's four nations to understand devolved government appetites for tackling cancer 'locally' and for resourcing their cancer services in future. Setting the context is important to understand exactly how the proposed one-to-one support fits with current and projected thinking across the UK. This section is split into subheadings relevant to cancer care across the UK.

5.1   Cancer survival

If England was to improve its performance in cancer survival to match the top performing EU country, it is estimated that around 10,000 lives would be saved every year. The English cancer strategy[20] highlights a number of actions that are required to move towards this:

- reduce the incidence of cancers which are preventable, by lifestyle changes
- improve access to screening for all groups and introduce new screening programmes where there is evidence they will save lives and are recommended by the UK National Screening Committee
- achieve earlier diagnosis of cancer, to increase the scope for successful treatment – diagnosis of cancer at a later stage is generally agreed to be the single most important reason for the lower survival rates in England; and
- make sure that all patients have access to the best possible treatment
- work with those living with and beyond cancer to ensure that everything is done to allow them to live as healthy a life as possible, for as long as possible

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[19] Improving Cancer Outcomes: An Analysis of the Implementation of the UK's Cancer Strategies 2006-2010 (Cancer Research UK, 2011) http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@pol/documents/generalcontent/cr_048863.pdf

[20] Improving Outcomes: A Strategy for Cancer (Department of Health, January 2011)

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- feedback on patient experience informs the design and delivery of services so they reflect what is important to all patients
- work to minimise inequalities in cancer that lead to some groups in society having disproportionately poor outcomes

The Department of Health (DH) aim is to reduce the number of cancer related deaths in the England by 5,000 each year by 2014/15[21]. The primary means for achieving this is through increasing the rates of early diagnosis. This includes diagnosis of patients who have survived a previous 'episode' of cancer. **Quality of life** has become an ever more prevalent issue within this strategy and it recognises that with potentially larger numbers of people **living with cancer** in future (due to the **ageing population** and growing issues around **obesity** and **lifestyle**) it will be critical to facilitate a more **personalised approach** in supporting cancer patients of the future.

Following the Government's announcement to focus the NHS on improving health outcomes which included improving cancer survival rates in comparison to other countries, Cancer Research UK produced a paper[22] that puts forward an explanation for the lag in England and makes recommendations for policy makers, commissioners and providers in England.

> *"A range of factors contribute to international differences in cancer survival, including: more advanced stage at diagnosis; delays in diagnosis and treatment; and treatment variation and comorbidity, particularly in older people. Overall, the most plausible drivers for improved survival appear to be diagnosis at an early stage, including through effective screening programmes, access to optimal treatment and improvements in the management of older people".*

The paper goes on to detail the 4 main influences on cancer survival rates, as illustrated below:

Figure 9: Possible drivers of international variation in cancer survival

Stage at diagnosis & delay	Treatment with curative intent	Patient factors	Tumour & physiological / biological factors
Stage at diagnosis	Surgery	Co-morbidity & fitness	
Patient delay	Radiotherapy	Age	
Doctor delay	Cancer drugs	Health related behaviours	
System delay	Co-ordination of treatment	Social & economic determinants of health	

Cancer is a progressive disease and so the 'stage' allotted at diagnosis is very relevant to patient survival. For example, the survival rates for breast cancer if diagnosed early (stage I) and if diagnosed at stage IV are 90% and 2% respectively. Different cancers have different survival rates – hence 'tumour and physiological/biological factors' also having an influence on survival rates in general.

> *"Whether patients attend screening or how quickly patients experience symptoms and seek help from the health system and then how quickly they progress through primary and secondary care to diagnosis and treatment are therefore logically important factors in determining outcomes" (Cancer Research & The King's Fund 2011)*

[21] Ibid

[22] How to Improve Cancer Survival: Explaining England's Relatively Poor Rates (Cancer Research UK & the King's Fund, 2011)

In terms of delays in initial diagnosis and referral, the paper uses a schematic developed by Olesen et al (Delay in Diagnosis: the experience in Denmark; 2009) which helps us to understand the process in moving from first symptom acknowledgement to the start of treatment and all the potential hurdles en route.

Figure 10: Categorising delays in diagnosis

Source: Olesen *et al* 2009
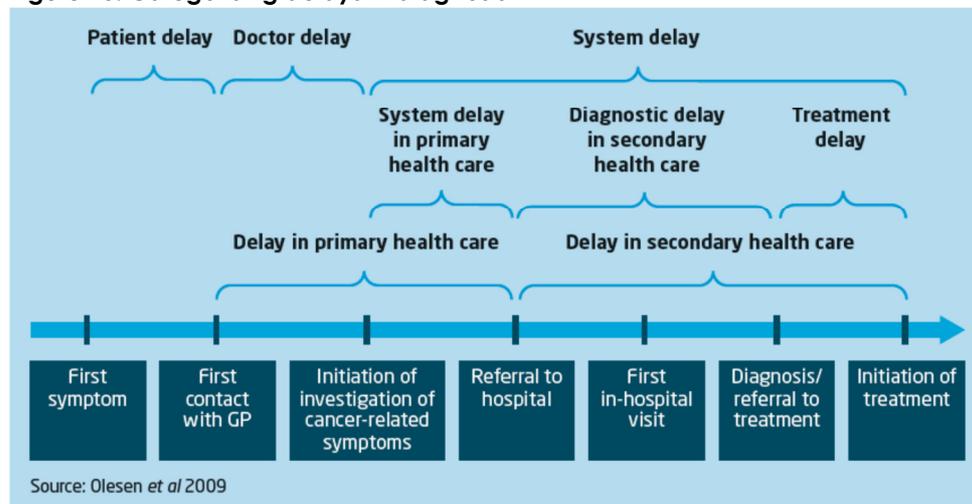
The paper argues that a combination of all 4 influences, as per figure 9, determines the overall survival rates for cancer and that improving performance under each of the 4 headings may influence England's performance in future. Some interesting statistics for England and Wales (based on 2000/01 observations) by tumour type are shown in figure 11. This emphasises the vast difference in survival rate across each cancer type.

Figure 11: Relative 5 year survival estimates based on survival probabilities observed during 2000/01 by gender and types of cancer (England and Wales) (Cancer Research UK 2009)

Source: Cancer Research UK 2009
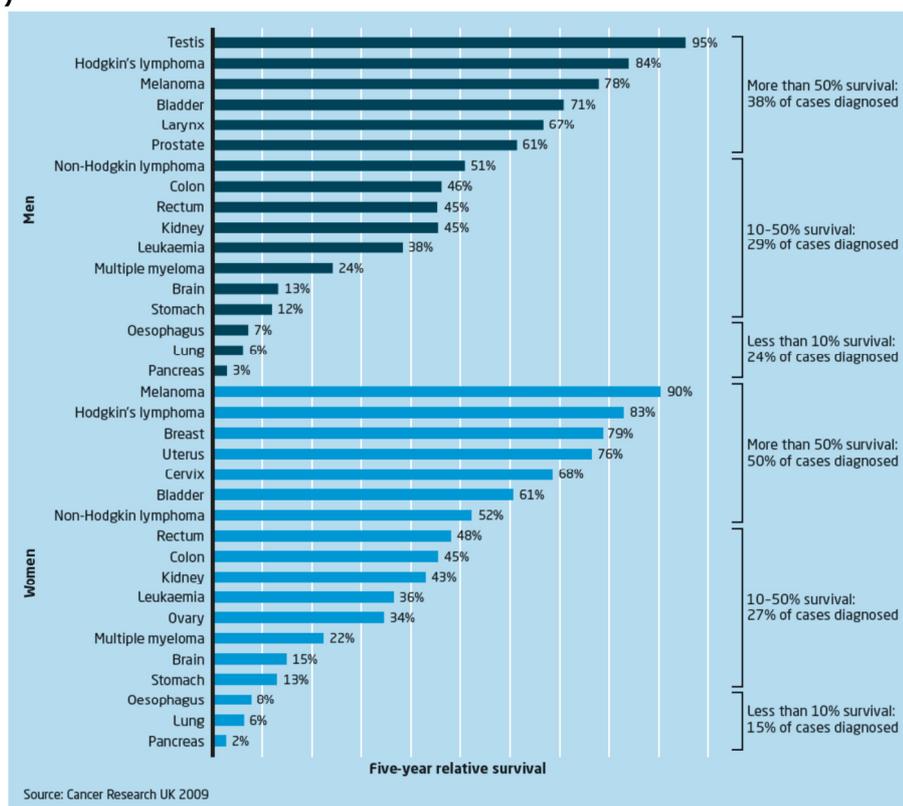
The prominent recommendations proposed in this paper included:

- **earlier stage diagnosis**
  This focused on changing attitudes in patients and potential patients; continuity of care; understanding signs and symptoms; accurate diagnoses and follow-up and co-ordinated secondary care
- **management of cancer in older people**
  The likelihood of developing cancer increases with age. Survival rates are particularly poor in older patients, although it is reported that 2/3 of survivors are 65+. Specific experience and needs of older people will need to be taken into account when working toward earlier stage diagnosis
- **health inequalities**
  The paper highlights the poor survival rates of those facing socio-economic disadvantage and possible ways to tackle these – largely through the provision of better and more accessible information
- **primary prevention and public health**
  Again, this focuses on information sharing and campaigns to reduce obesity, excessive drinking and smoking which all increase the incidence of cancer in the UK
- **research and analysis**
  The paper highlights a clear need to continue research in all of the above areas, especially research into effective interventions for earlier stage diagnosis
- **measurement and outcomes frameworks**
  Importantly, the paper emphasises that measures should go beyond survival rates and include stage at diagnosis; screening uptake; use of urgent referral pathway to more accurately illustrate the effectiveness of the NHS

These recommendations fit well with the premise of one-to-one support and what tailored support is designed to achieve. Looking at earlier stage diagnosis, health inequalities and public health, One-to-One Support postholders are in a good position to positively impact on these issues through better information sharing and individualised support packages.

The National Awareness and Early Diagnosis Initiative (NAEDI) was set up in November 2008 and is a third sector partnership between the Department of Health, National Cancer Action Team and Cancer Research UK. It was set up to get cancer awareness and early diagnosis on the local agenda. Its activity is organised into 4 work streams:

- achieving early presentation by public and patients
- optimising clinical practice and systems
- improving GP access to diagnostics
- research, evaluation and monitoring

The work carried out by NAEDI complements the One-to-One Support Intervention Project as it is working to raise awareness and to better prepare GPs to recognise and refer patients who present with cancer symptoms. This work aims to increase the number and accuracy of presentations and to empower the public to recognise symptoms and to see their GP early. This level of work across a broader spectrum of society, regardless of previous history with cancer, will support the more focused work that one-to-one support aims to deliver to patients from cancer diagnosis onwards. Raising public awareness about early cancer detection and better preparing GPs to recognise very early symptoms in patients all help to reduce later stage cancer diagnoses. Since October, over 19,000 GPs have been reached with messages about cancer and early diagnosis (NAEDI Newsletter February 2012) which increases the potential impact of one-to-one support to assist patients to return to their 'normal life' rather than focus on palliative end of life support.

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> *"The problem for GPs is that cancer is comparatively rare, often presents vaguely, and GPs are under extreme pressure to work fast and not to over refer. However we know we need to get better at early diagnosis: 1 in 4 patients with cancer in England still present as an emergency, and they have much lower survival rates than those referred by their GP. The difficulty we have as GPs is getting the balance right between not referring everything and yet not missing a diagnosis – and campaigns such as this can help. It's not only patients that fear cancer, GPs do too." (NAEDI, 2012)*

This has since been supplemented by new DH guidance for GPs in determining the symptoms and referral pathways for patients presenting with potential cancer symptoms[23]. Similar to those developed for England, guidelines to assist GPs in ensuring patients are referred quickly and appropriately have been developed for Scotland[24]. NAEDI also highlights the need for partnership working and for joining the dots in terms of provision in cancer care, information sharing and promotion – this is also high on the agenda for the One-to-One Support Implementation Project and, again, complements the work done by NAEDI.

This work is bolstered by the National Cancer Survivorship Initiative, which focuses on helping people who have been diagnosed with cancer beyond their treatment to cope with health issues and to monitor any symptoms that may lead to the recurrence of cancer or other illness. This is being piloted across 7 test sites in England. It aims to create change in the following ways:

- a cultural and attitudinal shift to focus on health and recovery
- a shift towards improving information
- a shift towards assessment and care planning
- to shift towards providing tailored care pathways based on risk of future problems associated with the type of cancer, the type of treatment and the particular circumstances of the individual
- a shift towards improved measurement through patient reported outcome and experience measures

Ipsos MORI conducted a first evaluation[25] of the initiative in October 2011 and has uncovered the following:

- 37% of patients did not feel that they had all the information they required to identify the signs and symptoms of the cancer coming back
- 5% said they had received information too late for it to have been any use
- 83% said they were confident in managing their own health
- only 21% of patients reported that they had a care plan
- only 38% of patients knew who to contact out-of-hours for support

It also raised a number of questions:

- absence of care plans – is this explained by a difference in terminology, and what do staff think about care plans and their usefulness?
- how patients feel about self-management of care – do they want to be responsible for managing their own care?
- what is currently driving patients who are self-managing their care and problems – is it their preferred option, or is there a lack of support?
- those groups who have had problems but have not done anything about it – by moving towards a greater degree of self-management do we risk this group increasing?

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[23] "Direct Access to Diagnostic Tests for Cancer: Best Practice Referral Pathways for General Practitioners"; Department of Health, April 2012

[24] Scottish Referral Guidelines for Suspected Cancer

[25] "National Cancer Survivorship Initiative: Evaluation of Adult Cancer Aftercare Services – Wave 1 Report"; Ipsos MORI, October 2011

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One-to-one support is designed to overcome some of these issues and questions by improving the information made available to patients, ensuring that their specific worries and symptoms are managed and minimised and to provide a continuous source of support throughout their cancer care pathway and beyond. The One-to-One Support projects will also help to answer some of the questions around patient opinion regarding 'self-management of care' and ascertain what is, on an individual basis, the most appropriate level of support for patients living with and living through cancer.

Scotland has developed a 'Detect Cancer Early Programme'[26] which is backed by £30M funding and aims to save around 300 lives a year. It will initially concentrate on 3 most prevalent cancers in Scotland – breast, bowel and lung cancer – and the following objectives will help to improve overall 5 year survival rates for people in Scotland diagnosed with cancer:

- to increase the proportion of people with stage 1 disease at diagnosis (as a proxy indicator of survival outcome) and to use performance against a HEAT Target as a lever for whole systems approach to improvement
- to improve informed consent and participation in national cancer screening programmes to help detect cancer earlier and improve survival rates
- to raise the public's awareness of the national cancer screening programmes and also the early signs and symptoms of cancer to encourage them to seek help earlier
- to work with GPs to promote referral or investigation at the earliest reasonable opportunity for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access
- to ensure there is sufficient capacity in the screening programmes to meet the expected increase in those choosing to take part
- to ensure that imaging, diagnostic departments and treatment centres are prepared for an increase in the number of patients with early disease requiring treatment
- to strengthen data collection and performance reporting within NHS Scotland to ensure progress continues to be made on improving cancer diagnosis, treatment, referral and survival.
- to facilitate further evaluation of the impact of public awareness campaigns on the stage of cancer at presentation and to contribute to research that establishes evidence for the link between late presentation and survival deficit

In Wales, the *Together for Health Cancer Delivery Plan* sets out a clear plan for the delivery of cancer services through 2016. It includes specific actions for Health Boards to take to improve performance in relation to early diagnosis, including:

- using National profiling data of cancer prevalence, mortality and survival rates to inform targeted action on particular cancers and communities
- raising public awareness of cancer symptoms needing prompt GP assessment
- raising GP awareness of symptoms to promote prompt referrals in line with national guidance, local pathways and waiting times standards
- working with GPs to introduce evidence based Risk Assessment Tools to help identify those at most risk of having cancer
- providing GPs with direct and prompt access to diagnostics to diagnose cancer
- auditing the pathway for each person diagnosed with advanced cancer and act on findings to improve services for early diagnosis
- developing acute oncology services to support the needs of people admitted as emergencies

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[26] Detect Cancer Early Programme (2011)

The plan also commits Health Boards to better meeting the needs of people affected by cancer, specifically:

- assigning a key worker to each person with cancer, from the point of diagnosis onwards, to coordinate their ongoing care
- reviewing and redesigning services recognising the changing needs of people with cancer and to deliver person centred services to meet ongoing needs as locally as possible in line with National Standards
- assessing the clinical and non-clinical needs (such as information needs on accessing financial, emotional and spiritual help) of people following a diagnosis of cancer and draw up and implement a care plan to be reviewed regularly
- providing each patient and GP with an "end of treatment" summary to inform the care plan
- supporting patient participation in cancer patient experience surveys and include action on the outcome in local cancer delivery plans
- planning and delivering co-ordinated services for metastatic cancer patients and measure outcomes

In Northern Ireland, the recent *Transforming Your Care Review* (also known as the *Compton Review*) reviewed health and social care across Northern Ireland. The review concluded that there were a number of principles that should inform the development and direction of health and social care services in across Northern Ireland, and that provision should:

- start with the individual
- look to a greater focus on prevention
- maintain care closer to home
- re-design primary care (for example through the development of GP led integrated care partnerships)
- re-shape hospitals

The findings from this review are directly influencing the commissioning and design of services across Northern Ireland, and it is clear that one-to-one support can help to deliver these for people living with cancer.

5.2   Patient experience

The Equality and Excellence white paper, published in 2010[27] feeds into much of the subsequent strategy development carried out by the Department of Health (DH) over the last two years. One of the most relevant aspects of the paper, in the context of one-to-one support, is that it makes a case for putting patients at the heart of the NHS through an 'information revolution' and affording them greater choice and greater control.

The vision for the future of the NHS is to 'put clinicians in the driving seat and set hospitals and providers free to innovate with stronger incentives to adopt best practice'. This vision is illustrated as shown below:

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Figure 12: Vision for the future NHS

System focused on improving outcomes

Robust economic regulation and quality inspection

Enhanced local voice

Clinically-led commissioning and payment for results

Empowered professionals working in autonomous providers

Informed patients exercising choice
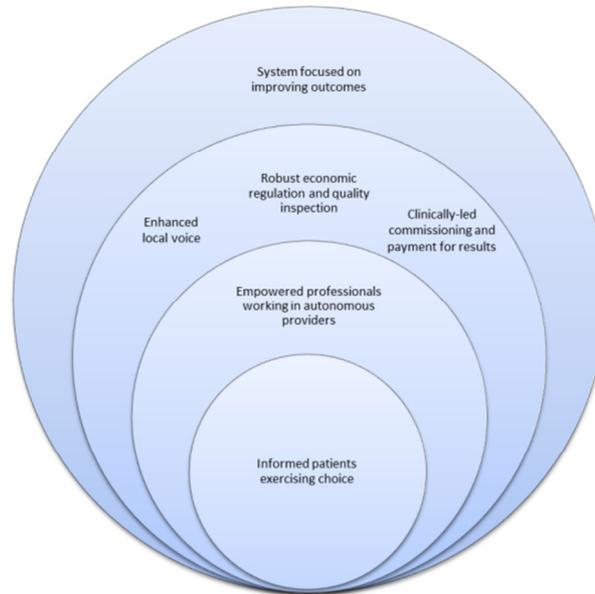
Department of Health, 2010

With current UK cancer survival rates ranking poorly within the Organisation for Economic Co-operation and Development (OECD), a follow-up strategy was published in 2011[28]. It aims to put patients, service users and members of the public at the heart of decisions about their care.

> *"Governments of the past have placed too much faith in the ability of a top-down hierarchy to deliver improved results for patients, through the micro-management of services from Whitehall resulting in the disempowerment of frontline staff and the disenfranchisement of patients. Too little faith has been placed in the power of local communities and frontline clinicians – and patients and service users themselves – to drive the improvements that we need to see".*

The strategy focuses on empowering individuals and communities, offering better information about the risk factors associated with cancers and how cancer survivors can be supported. It is about offering a greater degree of choice for patients, ensuring that they are actively involved in their care, strengthening the 'no decision about me without me' principle put forward by the DH, in hand with supporting local organisations and professionals to innovate and drive service improvements for all patients and service users.

The strategy also:

> *"…plans to harness the innovation and responsiveness of the charitable sector further in cancer care, both to build on the important work done to date to promote healthier lifestyles, encourage earlier diagnosis and provide information and support for those living with cancer, but also to broaden this important work out to encompass services which the voluntary sector may provide directly to GP consortia and to providers, both through the transition period and beyond".*

The strategy aims to see improvements in the outcomes which are particularly relevant for people living with and beyond cancer, such as:

- reducing ill health associated with cancer treatment
- reducing risks of recurrent cancer

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[28] Improving Outcomes: A Strategy for Cancer (Department of Health, January 2011)

- reducing the proportion of people who report unmet physical or psychological support needs following cancer treatment
- increasing the proportion of cancer survivors of working age who are able to work who are in work
- increasing the proportion of children or young people survivors who are in education or employment
- increasing the proportion of cancer survivors who are able to live independently

Cancer care is often one of the more complex pathways in the NHS, and recent evidence, from the National Audit Office (2005) and the Picker Institute (2009), highlights the challenges patients experience in accessing follow up care, with only half of patients in some cancer groups benefiting from such support. Those who report having the 'best' access to follow up care, often describe 'working hard' to get it. As noted above, but worth reemphasising, the most common problems in accessing this support are attributed to a lack of[29]:

- co-ordination
- local provision
- integrated and holistic care
- specialised services, either locally, or in some cases nationally

There is also recognition of the value that specialist nurses bring to the patient experience, particularly in relation to patient aftercare services.

> *"The CNS (CNS) was involved in the patient journey from early diagnosis through to follow-up post discharge. Lewis et al (2009) point out that nurse-led follow–up is a promising alternative to conventional follow-up which puts a major burden on outpatient services due to increasing cancer survivorship". (RCSI, 2010[30])*

The 2010 Cancer Patient Experience Survey highlighted that patients who had received support from CNSs reported having a better experience than those who did not. These findings were repeated in the recently published 2011-12 Cancer Patient Experience Survey, which similarly found that the impact of CNS is overwhelmingly positive, describing the impact that having a CNS makes on the care that patients receive as "substantial".

> *"Given the very high value placed on CNSs by patients, and the improved outcomes for patients who have a CNS, we would expect that this evidence and the pump-priming of new posts by cancer charity partners will lead to a continued expansion in one-to-one support both by CNSs as well as opportunities for care co-ordinator roles to be developed. Our ambition is that every cancer patient should have personalised and co-ordinated care".*

For the purposes of one-to-one support, we need to try to understand exactly how improved levels of individualised support might influence the desired outcomes as listed above. To seek to impact not only on 'quality of life' and the overall patient experience of follow-up care but also reap economic and socioeconomic benefits (more people continuing or returning to work, for example) is a challenge. There is no real evidence that suggests that this has been tested before and this project may be the first of its kind to do so, although it may be beyond the scope of the evaluation to do so. The DH suggests that this may be possible in terms of helping patients to return to 'normal life':

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[29] Cancer Follow Up Care: the views of patients and carers, Picker Institute, 2008

[30] Evaluation of the role of the clinical nurse specialist in cancer care; Royal College of Surgeons in Ireland, 2010
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> *"The way healthcare professionals communicate with those using the health service profoundly affects the experience of care for patients. Good communication can facilitate early diagnosis, improve self-management, reduce emergency admissions, reduce inequalities in access and provision of care, and support people to return to as normal a life as possible following cancer treatment. It is also critical to empowering patients to exercise informed choice". (DH, 2011)*

The strategy has a future focus that requires a cultural shift, focusing on recovery, health and well-being and cancer treatment. It concentrates on:

- personalised care – making sure that any model of care is patient tailored
- greater levels of patient assessment and information provision
- patient outcomes and experiences rather than clinical activity
- quality of life of those who are living with or have lived with cancer

All of these points fit well with the objectives of one-to-one support.

5.3   Self-management

Across all 4 nations there is a policy drive to encourage the facilitation of greater levels of self-management by patients. One-to-one support facilitates a more active role for nursing staff and is a potential 'enabler' for promoting and embedding better self-management across the UK.

> *"As the role of CNSs has evolved over many years they are in a key position, along with their Allied Health Professional and Cancer Consultant Nurse colleagues to lead developments to support patients to self-manage the effects of both their cancer and side effects such as fatigue, nausea and problems with eating that often accompany their treatment regime. The physical and psychosocial problems experienced by patients need to be addressed by rehabilitation, to effect timely discharge and enable independence in ways that contribute to quality of life and enable the patient to self-manage their own health"[31].*

A progress report on activity to date on Better Cancer Care[32] was published in 2010 and highlights the Scottish Government's recognition that there is still room for improvement in cancer care in Scotland. Better partnerships between public, private and voluntary sectors as well as increased access to CNSs and improved post-treatment outcomes through supported self-management of care have been highlighted as high priority challenges for Scotland's future.

The Northern Irish cancer service framework[33] sets standards about care across the patient journey. This includes:

- prevention
- diagnosis
- treatment
- on-going care
- rehabilitation
- palliative and end of life care

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[31] Better Cancer Care, An Action Plan, Scottish Government, 2008 http://www.scotland.gov.uk/Resource/Doc/242498/0067458.pdf

[32] Progress report on: Better Cancer Care, An Action Plan, Scottish Government 2008
[33] Service Framework for Cancer prevention, Treatment and Care

The Northern Irish strategy also involves the use of CNSs in aftercare and follows a similar logic to Scotland and England in developing coordinated care throughout the patient cancer journey:

> *"[We will] Coordinate care follow up - for patients who will be living with cancer as a chronic illness. This approach aims to support patients in self-management and avoid unnecessary hospital admissions. It involves CNSs working collaboratively with community colleagues in the provision of proactive health monitoring. When required, investigations can be arranged and quick access to medical consultation".*

Again, one-to-one support fits with this strategy, working to provide a more joined up and tailored approach to cancer care, early detection and patient support.

6   Pilot Lead Interviews – Thematic Analysis

A number of themes emerged from the pilot lead interviews, specifically in relation to:

- enablers and brakes
- recruitment processes
- training and education
- anticipated outcomes and impact
- sustainability

An overview of these is provided below.

6.1   Enablers and brakes

Stakeholder engagement was the most common theme to emerge from the pilot sites regarding what could enable or hinder the success of their projects. In particular, pilot leads highlighted the importance of having key influencers on board, acting as champions for the project. Clinical buy-in was cited as a key factor, both within the host organisation and also across the system – with particular reference to primary care. This engagement needs to be underpinned by clear communications – so that stakeholders understand why the postholders are there, what service the offer, and what the boundaries are of their roles. This will protect against any 'blurring of the boundaries', as one pilot lead put it, of their roles over time. To this end, some pilots are planning initial sessions where existing staff can come and hear about what the new postholders will do and the benefits they will bring. They will then seek to build on this by maintaining good relationships with key stakeholders – with GPs mentioned frequently.

> *"Clinical buy in from the services will be absolutely critical – both acute clinicians and GPs."*

> *"Having champions is key. We will get strong views from clinicians about the impact on patient management and care, and we will need to remain positive and upbeat in the face of this."*

> *"Clinicians currently are slightly confused about how the new roles will work – they will actually need to see them in operation."*

> *"It has been hard to get people engaged from community services, probably because cancer is less of priority in the community then long term conditions such as diabetes, CHD and so on. Also, they are being pushed with many other agendas. Unless they can be clear they are going to be funded to do it, they are not interested."*

The second most common theme related to the quality of the postholders themselves – namely ensuring that the right people with the right skill sets are recruited in the first instance, and then ensuring that the energy, enthusiasm and skills that they bring to their role are sustained over the course of the project. One pilot lead commented that this would be crucial in winning over the 'critics'. Another felt that this will build the confidence and trust of other staff in 'letting go' where they need to in order to allow patients to be treated and cared for in a different way under the new model.

A third key theme was alignment. This refers to the alignment and positioning of the new posts with organisational priorities, other service improvement work, and existing services. This was about ensuring that the new posts are 'pushing the right buttons' in terms of the needs and direction of the organisation. For example, one pilot lead commented that their project was much more likely to be successful if they could demonstrate and communicate the contribution of the project to the organisation's existing work on reducing unnecessary outpatient follow ups.

"People need to see that it works, and that it works with relative ease i.e. that it is going to make their job easier, not more difficult."

6.2   Recruitment process

Some pilots had not yet started their recruitment process, or the pilot lead had not been involved in the process and therefore was not able to comment. Of those that did comment, experiences of and learning from the recruitment process were mixed. Some pilots said that they had received an extremely good response and had gained an excellent pool from which to select their postholders.

This was particularly true of support worker roles where several pilots received a substantial number of applicants (50+ at a number of pilots). Offering the option of secondments as well as fixed term contracts appeared to help boost response rates. In contrast, other pilots had found the process more of a struggle – with one pilot lead considering that not being able to offer full time posts was a hindrance. The Western Health and Social Care Trust pilot found that strict HR processes in Northern Ireland were slowing the recruitment process for them.

The sites that experienced difficulty recruiting reported:

- a lack of good quality candidates, with particular issues around recruiting to the community nurse posts
- delays in recruitment due to internal procedures/not attracting the right calibre of candidate
- recruitment difficulties resulting in changes to sessional working and changing to full time roles

One site in particular reported having difficulties recruiting to of the nursing and complex case manager posts, and identified the main barrier as being the limited timeframe for the post (two years). Specifically, given the current economic circumstances facing the NHS, the pilot lead at this site believes concern over the lack of posts at a similar grade being available at the end of the pilot process (whether full time or on secondment) was discouraging candidates from applying.

Several sites also mentioned that that many applicants associate Macmillan posts with palliative care – with the result that their understanding of the role is often at odds with what is required. Where they have re-advertised the posts, the pilot leads have gone to great lengths to emphasise that the service will focus on supporting cancer survivors to try and overcome the association with palliative care.

Most pilots shortlisted candidates from applications and then undertook an interview process.

6.3   Training and education

The majority of pilots have sent, or will be sending, their postholders on the induction and mandatory training process for their organisation, and encouraging them to meet and build relationship with key local stakeholders. Other elements of the training and education package for postholders vary by pilot site. A number of pilots were planning to access Macmillan courses and materials – for example the Introduction to Cancer course, and a range of e-learning modules. Some pilots had prepared starter packs for their postholders, containing key information and resources. Other pilots are focusing more on non-desk based learning – through shadowing, mentoring and coaching. Only a small minority of pilots commented on the need to develop individualised training plans based on the needs of the specific postholder, although those sites that have not yet recruited indicated that they will review individual training needs once they have candidates in place.

6.4   Outcomes and impact

Pilot leads' articulation of the expected outcomes from and impact of their projects maps very well to the logic model for the programme. A key overriding theme was an expectation that the new model will deliver seamless and holistic care.

Regarding patient experience and outcomes, there was strong coverage across the pilots in terms of expected outcomes related to:

- improved satisfaction
- single point of contact
- better information
- better signposting
- proactive patient management
- less isolation
- support for self-management

"Some people are held in an acute setting for too long. This disables them rather than empowering them to take responsibility for their own health. We want to both give patients the knowledge, and change the staff culture to enable this to happen."

With regard to clinical outcomes, pilot leads articulated benefits in terms of improved quality of life and, to a lesser extent, better identification of the signs of recurrence. The pilots also include a strong focus on improving knowledge amongst primary care providers, and providing services through primary care in community settings.

The more primary care projects are expecting outcomes around improving the frequency and quality of cancer reviews taking place in primary care. This is a key additional outcome to track as part of the evaluation and we are extending the data collection form to capture this, and propose that the programme logic model should be re-shaped accordingly.

Regarding improved productivity, there was good coverage in relation to:

- more cost-effective skill mixing, freeing up CNS time to focus on more complex cases
- reducing unnecessary admissions
- reducing unnecessary GP visits
- reducing unnecessary outpatient follow ups

"We hope that patients will be accessing much more support in a community rather than a hospital setting. We also hope patients will start to see the end of their treatment as a transition into a different kind of support rather than a stop-dead. When they want or need to get back into the system, they will be able to more easily. But at the same time patients who are needlessly coming back into the system for routine follow up will be supported in a different way."

Comparatively less pilot leads communicated the expectation of reducing length of stay. Nevertheless it remains an area where the projects could have an impact and warrants tracking over the course of the evaluation.

6.5   Sustainability

Four key themes emerge from an analysis of pilot leads' early views on factors that will influence the sustainability and future extension of the projects:

- ownership and engagement
- evidence that the new model works
- integration
- commissioner buy-in

Several pilot leads emphasised the need for building and sustaining ownership of and commitment to the new model, and saw this as a key factor in sustainability. One element of this is about demonstrating to staff in connected services that these posts make their lives easier rather than more difficult.

"Ownership is critical."

One pilot lead described the need for evidence that the new model works from both economic and quality perspectives, and for this to be quantified:

"If the evaluation can capture the success in a tangible, quantified way – starting with the economic case and then moving to the quality case – then that will support extension and roll out"

Emphasising this point, another pilot lead spoke of the need to translate the benefits into financial savings.

By integration, pilot leads meant developing good synergy between the postholders and other services, ensuring that the posts are seen as an intrinsic part of service provision rather than a 'bolt on'. One pilot lead spoke of the need for the posts to become 'part and parcel' of normal delivery.

"The roles must not be additional. They need to be integrated, and shown to be supporting roles rather than taking work off other staff. The culture needs to ensure that people don't sit back as a result of the new posts coming into being, therefore losing some of the additional benefit. There needs to be good synergy with other services, linked to training, and fitting together across the piece."

Some pilots are extremely cognisant of the need to establish and maintain strong commissioner buy-in, and one pilot commented that they are already in dialogue with commissioners regarding the future of the posts. Another pilot (Queen Victoria Hospital) has already obtained a commitment that the posts will continue to be funded on an ongoing basis. If the piloted model is found not to work well, they will redefine the roles.

7 Reviewing Existing Research – One-to-One Support Mechanisms in Long-Term and Chronic Illness

> **Key points summary**
>
> - emerging consensus that the effective management of complex chronic diseases represents one of the greatest challenge for healthcare systems
> - there have been a limited number of recognised 'models' of care in this area – but there still remains a significant requirement for better integration of healthcare providers and better co-ordination of care
> - one-to-one support builds on this experience, and this pilot therefore represents an opportunity to implement and evaluate the impact of introducing this model of care on the people living with or beyond cancer, and healthcare systems across the UK

There is now an emerging consensus that the effective management of complex chronic diseases represents one of the greatest challenges facing health systems. There is also a substantial consensus that this will require new ways of delivering healthcare, involving integration of care providers or, at least, much closer coordination of their activities[34]. Cancer is part of this and the application of different systems of care management across Europe and beyond all shows that integration and a 'whole life' approach is important in arranging services and outcomes for patients. There are subtle differences in approach, however, sometimes due to different funding systems (public versus private) and varying demographic, social and economic factors.

Many approaches to coordinating chronic disease management have been implemented. These can be differentiated based on the locus of control (government, professional bodies or commercial entities), the level of integration (single versus multiple care settings and providers), funding (public, private and part payment), methods (regulation, risk stratification, case management, decision support and supporting self-care) and target audience (whole population, service users, professionals, institutions and governments)[35]. There are a limited number of recognised 'models' of care and these are discussed briefly in turn below.

7.1 Chronic Care Model

Almost half of all people with chronic illness have multiple conditions. As a result, many managed care and integrated delivery systems have taken a great interest in correcting the many deficiencies in current management of diseases such as diabetes, heart disease, depression, asthma and others.

Those deficiencies include:

- rushed practitioners not following established practice guidelines
- lack of care coordination
- lack of active follow-up to ensure the best outcomes
- patients inadequately trained to manage their illnesses

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[34] Caring for people with chronic conditions; a health system perspective, Nolte & McKee, 2008
[35] How can chronic disease management programmes operate across care settings and providers? Singh, 2008

Overcoming these deficiencies will require nothing less than a transformation of health care, from a system that is essentially reactive - responding mainly when a person is sick – to one that is proactive and focused on keeping a person as healthy as possible[36]. The chronic care model was originally developed in the late 1990s in the United States but has since been adopted worldwide, to varying degrees. The model recognises that a significant proportion of care takes place outside formal healthcare settings and highlights the 6 elements that are deemed necessary to deliver initiatives in chronic care, as shown by figure 12 below.

Figure 14: The Chronic Care Model (CCM)
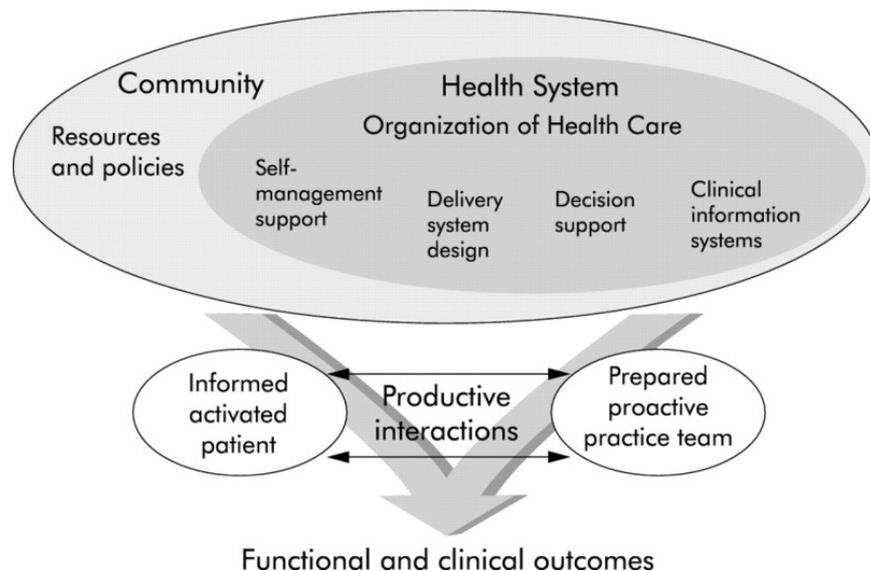
In 2003, the Improving Chronic Illness Care[37] organisation and a small group of experts updated the CCM to reflect advances in the field of chronic care both from the research literature and from the scores of health care systems that implemented the Model in their improvement efforts. Based on more recent evidence, five additional themes were incorporated into the CCM:

- patient safety (in Health System)
- cultural competency (in Delivery System Design)
- care coordination (in Health System and Clinical Information Systems)
- community policies (in Community Resources and Policies)
- case management (in Delivery System Design)

The call for case management of patients to foster a whole system approach is very relevant to one-to-one support and fits well in designing care delivery systems, adding value by providing a sustainable point of contact for those living with a chronic illness. In countries where primary care is based largely on multi-professional teams of physicians, nurses and other health professionals and where patients are registered with a specific primary care facility, there has been a progressive increase in the role of nurses in managing many chronic diseases. This commonly takes the form of nurse-led clinics, discharge planning and/or case management. This has been the case in Sweden and England and, more recently, the Netherlands[38].

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[36] See www.improvingchronicillnesscare.org
[37] www.improvingchroniccare.org
[38] Managing Chronic Care: Experience in 8 Countries, Nolte, Knai, McKee, 2009
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Key functions of on-going follow-up and support include monitoring of status and self-management, encouragement and facilitation of regular clinical care, encouragement and motivation of self-management, and facilitating skills for coping with changes in circumstances or emergent problems. Key features of on-going follow-up and support to fill these functions are being available on demand; being proactive in maintaining contact and preventing individuals from "falling between the cracks"; having personal, motivational, and consistent key messages; and being inclusive of a wide range of resources and settings[39].

7.2   Kaiser Permanente Model

The Kaiser model is based on the chronic care model and stratifies patients with long-term conditions (LTC) into 3 groups (as shown by the levels in figure 13 below). With three levels of care incorporating:

- case management for those patients who are very high intensity users of unplanned secondary care
- disease/care management for patients who have multiple long-term conditions (high risk patients needing regular routine follow-up)
- supported self-care for the majority of the chronic care population (people with a chronic disease who are at low risk of complications and hospitalisation)

The two levels of care at the top of the triangle will require more professional intervention to be delivered effectively. Underpinning this model is an emphasis on promoting better health in the population as a whole by providing advice and support about healthy choices. This broader focus on lifestyle is based on the premise of the importance of preventing the condition of patients from deteriorating and consequently requiring a more intensive level of support[40].

Figure 15: Kaiser Model
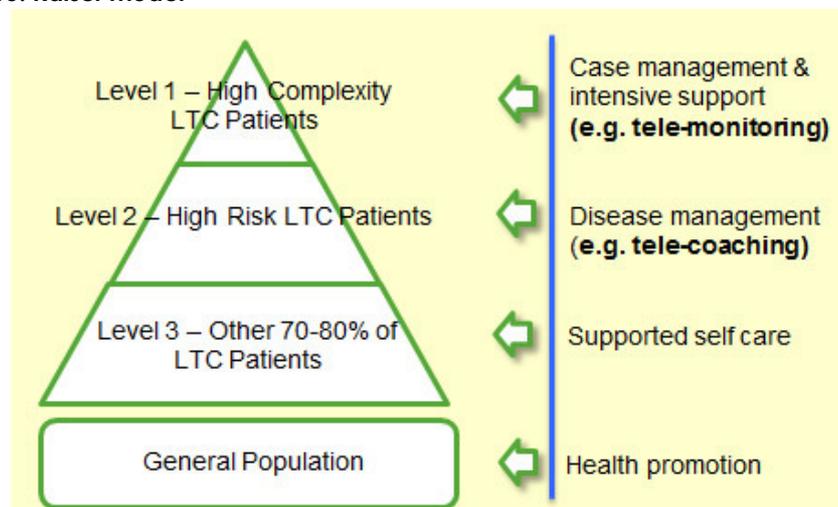
Source: Yorkshire & Humber HIEC

This is the approach adopted by the UK in general and clearly identifies a place for one-to-one support or case management. This intensive level support has been found to be most effective when delivered in conjunction with disease management and when delivered with one or more additional educational, reminder, or support interventions[41].

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[39] On-going follow-up and support for chronic disease management in the Robert Wood Johnson Foundation diabetes initiative Fisher et al 2007
[40] Self-care and Case Management in Long-term Conditions: The Effective Management of Critical Interfaces, Challis et al, 2010
[41] The effectiveness of disease and case management for people with diabetes: A systematic review, Norris, 2002

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Past studies have highlighted some of the benefits of intensive support and case management in chronic care patients. One recent study[42] noted the positive impact that nurses have had on five health outcomes:

- objective clinical measurements
- quality of life and functionality
- patient satisfaction
- adherence to treatment
- self-care and service use

When it comes to oncology, case management is mainly used in the follow up of abnormal cancer screening and in cancer treatment, but it is not yet common in the rehabilitation of cancer patients[43]. Work in the United States[44] has shown that the incorporation of community health workers in cancer care has had positive impacts on patients. A report[45] for Medicare and Medicaid Services from Brandeis University on cancer prevention and treatment among minority populations stated that:

"Community health workers…can offer linguistic and cultural translation while helping beneficiaries get coverage, develop continuous relationships with a usual source of care, understand current risk behaviours, motivate them to engage in risk management, and receive support and encouragement for maintaining these efforts."

Interventions incorporating community health workers have also been found to be effective for improving knowledge about cancer screening as well as screening outcomes for both cervical and breast cancer. This shows the strength of a one-to-one approach where continuity of care and established relationships with professionals can help to change mind-sets, health habits and a greater propensity to self-manage care. Elsewhere, the adoption of nurse-led care is also high on the agenda and nurse-led clinics are now common at primary healthcare centres and in hospital polyclinics across Sweden, for example.

The main reasons behind the growth in nurse-led clinics are both economic and to create new career opportunities for nurses. One other aspect is the development of a more patient-centred system that facilitates access, through telephone consultations and support for elderly persons with communication difficulties[46].

Population management is one of the factors that enables the Kaiser model to contribute to the avoidance of inappropriate use of hospitals. This is summarised in the philosophy that 'unplanned hospital admissions are a sign of system failure'. Put another way, Kaiser takes the view that patients who require hospital treatment that has not been planned have not received optimum care at an earlier stage in their illness. It seeks to provide optimum care through the use of evidence based guidelines and by managing care to reduce unacceptable variations in practice[47].

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[42] Structured review: evaluating the effectiveness of nurse case managers in improving health outcomes in three major chronic diseases, Sutherland & Hayter, 2009

[43] Case management in oncology rehabilitation (CAMON): The effect of case management on the quality of life in patients with cancer after one year of ambulant rehabilitation. A study protocol for a randomized controlled clinical trial in oncology rehabilitation, Bachmann-Mettler et al, 2011

[44] Addressing Chronic Disease through Community Health Workers: A Policy and Systems-Level Approach, National Center for Chronic Disease Prevention and Health Promotion

[45] Brandeis University. Evidence Report and Evidence-based Recommendations: Cancer Prevention and Treatment Demonstration for Ethnic and Racial Minorities: Brandeis University; 2003.

[46] Caring for people with chronic conditions; a health system perspective, Nolte & McKee, 2008

[47] Working Together for Health: Achievements and Challenges in the Kaiser NHS Beacon Sites Programme, Ham 2010

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One-to-one support follows this thinking in that it provides a mechanism for patients to access care and advice in the community rather than in a hospital setting. The argument for nurse-led case management of patients in this way is further strengthened by research, including a review of case management programs[48] where six out of six studies showed improved outcomes compared with controls. For instance, nurse telephonic case management of congestive heart failure patients discharged from the hospital was associated with increased quality of life and markedly reduced hospital readmissions compared with controls. Telephonic case management of coronary heart disease patients yielded reduced smoking, lowered cholesterol, and increased use of exercise compared with controls. Case management of people 75 years of age or older by nurse practitioners performing home visits resulted in less progression of functional disability and reduced permanent nursing home stays compared with controls.

Multidisciplinary care has been referred to as an "extension" of case management in that it also normally involves the development of treatment plans tailored to the medical, psychosocial and financial needs of patients, but in contrast to case management uses a broader range of medical and social support personnel (including physicians, nurses, pharmacists, dieticians, social workers and others) to facilitate transition from inpatient acute care to long-term outpatient management of chronic illness (Krumholz et al. 2006). The Macmillan One-to-One Support Implementation Project will provide a balance of cancer professionals to work together and join up services across healthcare and supply patients with a better quality proactive form of care.

There is substantial consensus worldwide that new ways of delivering healthcare, involving integration of care providers or, at least, much closer coordination of their activities is required. Yet beyond these areas of agreement, there is much less consensus about how this should be achieved[49]. This puts Macmillan in a position to demonstrate the value of one-to-one support through its pilot sites and subsequent adjustment and roll out across the UK.

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[48] Interventions to improve chronic illness care: evaluating their effectiveness, Bodenheimer, 2003
[49] Caring for people with chronic conditions; a health system perspective, Nolte & McKee, 2008
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8   One-to-One Support – Pilot Projects

8.1   The cohort

There are 16 One-to-One Support pilot sites across the UK, 15 of whom will be included within this evaluation (one site is being evaluated separately as part of a wider initiative). Each project in the initial pilot is described below, with a fuller pilot profile provided in Appendix 2. Please note the following abbreviations:

- MCCM = Macmillan Complex Case Manager
- MNCC= Macmillan Nurse Community Care
- MNPC= Macmillan Nurse Primary Care
- MSW = Macmillan Support Worker
- CNS= Clinical Nurse Specialist

Applications to become a pilot site were broken down into two 'waves', and wave one/two sites are identified as appropriate below.

The pilot sites provide good coverage across the UK, with ten in England, two in Wales, two in Northern Ireland and one in Scotland. The short summaries below provide details on the number and type of Macmillan role each site will host, some background on the site, and their aims/objectives for the posts.

It is worth noting that the proposed approach and aims and objectives highlighted by the sites are very much in line with Macmillan's anticipated outcomes for the pilot (as set out in the programme logic model, Appendix 3). While it is too early to tell if some of these outcomes will be met (for example the extent to which the roles are accepted by peers and seen as credible and as complimentary to existing roles), the early indicators are positive, specifically in relation to:

- proposing to make changes to the care pathway that provide more joined up services that better meet the needs of people living with and beyond cancer
- maintaining a focus on improving the quality of care and patient experience
- improving clinical outcomes
- improving productivity

The fifteen pilot sites therefore offer an excellent opportunity to evaluate the impact of introducing the One-to-One Support roles into a range of healthcare settings and policy contexts, and evidence the extent to which they deliver the anticipated outcomes and impacts.

8.2   Wave One pilot sites

8.2.1   Bristol Integrated Cancer Services (Avon, Somerset & Wiltshire Cancer Network)

As part of the Avon, Somerset and Wiltshire Cancer Services Network, four organisations are forming a partnership to deliver the One-to-One Support pilot for Bristol. These are:

- University Hospitals Bristol NHS Foundation Trust (UH Bristol)
- North Bristol NHS Trust (NBT)
- South Gloucestershire Community Health Services (SGCHS)
- Bristol Community Health Community Interest Company (BCHCIC)

UH Bristol and NBT provide cancer services for all Bristol patients (population of 800,000 combined for central and greater Bristol). BCH CIC/SGCHS currently provide a dedicated service for end of life care and provide support for patients undergoing cancer treatment in secondary care settings.

The partnership will pilot 3 MSWs, 2 x 0.6 CCMs and 2 x 0.6 MNCC. These pilot posts will form a virtual team (embedded in their local service delivery structure), enabling clear referral and communication pathways for shared cancer patients as they move across the city at diagnosis and during/after treatment.

Cancer patients will have a holistic needs assessment carried out whilst they are under the care of the Acute Trusts (UH Bristol and NBT), usually this will be done by a CNS following surgery or during chemotherapy/radiotherapy. Patients will then be risk stratified into red, amber or green and their on-going care needs will be structured in relation to this. The MSW will:

- provide a single point of access for patients
- organise post treatment self-management programmes (as guided by clinical staff)
- coordinate care for patients with non-complex needs (those stratified 'green')
- enable navigation of the health and social care system for cancer patients
- coordinate on-going care/support through direct links to the community nurse/CCM posts

Patients with shared care needs (amber) will be referred to the Macmillan NCC posts for additional support. Those patients identified as having complex care needs (red) will be referred to the CCM posts. The services provided by these posts will:

- support people in regaining as normal a life as possible after treatment
- minimise the risk of developing further cancer-related problems
- give information, advice and support about long term effects of treatment and how to minimise the effects
- provide appropriate advice and support in the early identification of advancing disease, and how to manage this effectively
- enable people to re-access cancer and specialist services without delay should they need to

It is anticipated that this pilot will provide significant quality benefit for the shared patient population. More appropriate use of restorative health resources is also predicted through this pilot, resulting from:

- reduced readmissions into acute trusts
- efficiencies in acute trust CNS workload, through central triage and single point of access for patients
- reduced GP appointments
- minimised risk of patients developing further cancer related problems
- early detection of signs of deterioration, recurrence or long term effects of treatment
- enable appropriate rapid re-access into secondary care as required
- ability for primary/community care to access specialist oncology advice and support

This project is being led by the University Hospital Southampton NHS Trust. The overall aim of the pilot is to build upon the NCSI cancer after care project which has been in place since November 2009. One Macmillan CCM and two Macmillan Support workers will be employed as part of this pilot project. NHS Southampton supports the needs of around 250,000 people living within a relatively small geographic urban area, with significant health inequalities and health generally worse than the England average.

Specific objectives include:

- to expand the use of risk stratification which informs levels of care, patient pathways and effective aftercare models
- to design and pilot the Macmillan SW role which will enhance patient experience in the level 1 supported self-managed pathways for breast, colorectal, testicular, endometrial cancers
- redesign care pathways for patients with advanced and progressive disease (breast and gynaecological – level 2 and 3 care) and to pilot the Macmillan CCM role to provide supported and integrated care across care settings

The new pathway for the pilot of the CCM role will be for patients with advanced and progressive disease (breast and gynaecological cancers) and for patients who have completed curative treatment and are on self-managed follow-up pathways. The two new roles are intended to enable the new pathways as follows:

- care coordination – streamline and coordinate survivor aftercare (complementary function within the current MDT) of clinical and non-clinical services and to ensure the patient is seen by the appropriate person, and in a timely manner
- contribute to the care of patients on supported self-managed pathways
- coordination of self-management interventions: plan, organise, coordinate, evaluate, and support delivery of the annual programme of self-management support interventions for all patients in level 1 pathways

Complex case management is going to enable new pathways for women with secondary disease to experience coordinated, supportive care for their varying intensity of needs. It will be community based and straddle and integrate specialist MDTs with targeted proactive primary and social care services. This will involve anticipatory care planning which will lead to improved quality and patient experience.

8.2.3   *Berkshire Healthcare NHS Foundation Trust (BHFT) (Thames Valley Cancer Network)*

This pilot will support 1 CCM and 1 MSW. These roles will be developed within the Slough locality but may extend to the wider area of East Berkshire once the care pathways have been established and a level of the demand verses capacity determined. Slough locality has many challenges including: areas of deprivation, a multi-cultural population, poor quality and overcrowded houses, general ill health, several single handed/small GP practices and cancer patients receiving treatment from multiple cancer centres including London hospitals. This leads to a complex cancer pathway with patients often uncertain how to access local support.

The role of CCM will be pivotal to addressing these unmet needs, through collaboratively working with the local cancer teams, to establish a robust end of cancer treatment pathway, building on the principles of an identified key worker, who patients feel is available and knowledgeable regarding their needs, and ensuring a seamless transfer of care from hospital focused care to community care.

The overall aim of the BHFT project is to develop a robust community focused cancer aftercare pathway linking in with the existing cancer treatment pathway. The objectives of this project are to:

- support patients to navigate through the complexities of cancer care within East Berkshire given the number of organisations involved
- empower patients to maximise their quality of life through proactive self-management, signposting to existing support services and clinical support from CCM
- support patients with long term consequences of cancer treatment
- act as a resource for other community professionals and Primary Care supporting patients with cancer and other co-morbidities
- recognise possible signs of deterioration and/or recurrence linking with appropriate cancer MDT or timely referral for acute care admission
- utilise the project to scope the potential number of patients requiring aftercare and level of care required to inform future developments within East Berkshire

8.2.4   Queen Victoria Hospital NHS Foundation Trust (QVH) (Kent & Medway, SWSH and Sussex Cancer Networks)

This pilot will support one Macmillan CCM and one Macmillan SW. QVH works as a tertiary centre, across three cancer networks, and provides the surgical aspect of patients' treatment plans for major head and neck, malignant melanomas, skin and breast cancers often involving complex reconstructive surgery. Often patients who undergo surgery at QVH have complex discharge arrangements. Currently this involves a multitude of agencies which are not always aligned, especially when the patient has come across county boundaries.

The ability to ensure that complex cancers across the region are managed in a timely manner can be challenging and the current expectation for one Macmillan nurse, for each of the speciality areas, to manage these patients, while also attending network and MDT meetings can at times be unrealistic. QVH feels there is an opportunity to improve coordination with local and specialist MDTs and other agencies to support the management of patient care from diagnosis through to completion of treatment.

This project will pilot two roles:

CCM - would provide an opportunity to observe how support can be delivered to patients and their relatives, through developing links with multiple healthcare and social care professionals involved across a wide regional area.

The CCM would also provide a focus point for a more holistic and seamless passage of care through all stages of care, linking with primary care and reducing hurdles to improve the overall experience. They would also be responsible for providing regional education and delivering service redesign, as well as ensuring that commissioners of cancer pathways are involved to streamline processes across organisations particularly for complex cases in Sussex and Kent.

MSW – would complement and strengthen the existing team comprising of CNSs and the Information Centre Manager. The support role would be able to work alongside the centre to provide a single access point for patients and their carers for information, education and support by fielding general calls. This in turn would free up time for the CNSs and the CCM to deal with more complex patient needs.

The aim of the local pilot site would be to provide an integrated model of cancer support, from a tertiary centre, that provides regional holistic expert care, for complex cancers covering the time the patient is referred through to discharge. The objectives that QVH would anticipate being met include:

- all patients having access to a central Macmillan cancer nurse for support with improved links between organisations
- all patients seen at QVH having a single point of access and patients experience is not hampered by region
- reduced inappropriate admissions of cancer patients by allowing patients to re-access services without delay
- increased number of patients feeling a sense of leading as normal a life as possible with cancer
- provision of expertise and training for relatives, carers and professionals
- identification of gaps in services particularly in community to commissioners via the cancer networks
- release CNS time to focus on where their specialist skills are most needed
- increase skill mix in cancer team

The appointment of both the CCM and MSW would provide cancer patients a holistic model of care. The two roles would be incorporated into the wider team operating out of a central hub based at QVH. This would enable the current cover provided by QVH to be extended both from referral and beyond discharge. This model would:

- aid the transition of patients and those around them from the time they are booked for surgery through to discharge into the community
- extend the expertise from a tertiary centre to the community by working with and training staff
- enhance the care the patient receives in order to reduce unnecessary admissions to hospital and improve life beyond cancer
- complement the newly opened Information Centre by providing a single access point for patients and their carers for information, education and support by fielding general calls
- release CNS time onsite and allowing the CCM to deal with more complex patient needs as referred by the MSW
- facilitate liaison with secondary providers and patients to co-ordinate dates for surgery involving visiting consultants

8.2.5 Newcastle upon Tyne Hospitals NHS Foundation Trust (North of England cancer Network)

This pilot will support 0.6 of a Macmillan Nurse (Community Care) and 0.6 of a Macmillan Nurse (Primary Care), 0.6 of a Macmillan CCM and 1 Macmillan SW.

Newcastle upon Tyne NHS Foundation Trust is one of the largest NHS Trusts and Cancer Centres in the UK, with acute and community services including 29 GP practices in the area, covering a population of 300,000. In partnership with Macmillan Cancer Support, the PCT commissioning arm has also just appointed two Macmillan GP Facilitators.

The District Nursing Services, Community and Trust Specialist Palliative Care Teams are under one management structure and reporting directly to the Head of Patient Services who also has a Corporate Lead Cancer Role resulting in a very streamlined and responsive service for patients.

The aims of the One-to-One Support service are to improve patient outcomes and experience for people living with and beyond cancer so that they are supported to live as healthy and active a life as possible for as long as possible. Objectives:

- identify, assess and meet needs of patients at key points of their cancer journey
- measure patient experience and quality of care taking into account the nine Macmillan outcomes that were identified by patients as being of paramount importance
- develop risk stratification tool as per NCSI initiative (supported self-management, shared care or complex care)
- develop new models of follow-up e.g. best practice from long term conditions model, identification in primary/community care of patients receiving anti-cancer treatment
- actively engage with the evaluation process
- the steering group will explore sustainability and transferability of the service
- develop and deliver education opportunities to other health, social and voluntary partners

The current cancer care pathway is predominately secondary care focused, however the majority of patients spend most of their time at home in community/primary care. Patients are referred via community/primary care into secondary care where they are diagnosed. Patients who are undergoing anti-cancer treatment have open access via a 24/7 hospital telephone helpline. Patients are supported at home by community services when specific care needs identified – this could involve GP, District Nurse, Practice Nurse and Social Services. Any routine follow-up is undertaken in secondary care by the patient's cancer team.

There is clearly a gap where currently patients' needs are not being assessed, identified or care plans developed. The pilot will facilitate the development of a risk stratification tool that would involve the clinical team and the patient making the decision together, regarding the best form/model of aftercare and addressing these unmet needs.

It is anticipated that both new postholders would work closely with acute colleagues, linking in with site specific nurses and ward staff ensuring patients who would benefit from the One-to One service are given that opportunity. The Macmillan support worker would link into all of the roles, taking on the patients at level 1, encouraging and supporting self-care with open access back to the team.

The Macmillan CCM will work with patients with needs at level 3, linking in to all professionals and organisations. They will also provide clinical and professional support and act as a role model to the team. It is expected that part of the role will also encompass education to other care providers including patients.

8.2.6   The Royal Marsden NHS Foundation Trust (SW London Cancer Network)

This pilot will support 0.6 of a Macmillan Nurse (Community Care) and 0.6 of a Macmillan Nurse (Primary Care), 0.6 of a Macmillan CCM and 2 Macmillan SWs. The aim of the project is to test the four new roles developed by Macmillan to support a sustainable aftercare model which integrates primary and tertiary care and provides the most effective and accessible care for people affected by cancer. The roles are specifically:

1. Macmillan SW based in the hospital
2. Macmillan Nurse Primary care
3. Macmillan Nurse Community Care
4. Macmillan CCM

The support worker will cover an MDT and the community posts will cover a cluster of GP practices.

The objectives of the project are:

- implementation of a new aftercare model for people with cancer which crosses both acute and primary care settings
- to improve patient-reported outcomes and patient experience
- to have greater GP/community involvement with people living with and beyond cancer
- development of primary/tertiary care liaison model
- linking patient pathways to HNA and care planning (according to patient risk stratification) in acute and primary care
- improved communications (and documentation) between GPs/community care, acute oncology services, social care and the patient and family
- reduced unplanned hospital admissions and length of stay for people living with and beyond cancer treatment
- to evaluate the feasibility, processes and impact of the new roles as well as the new aftercare pathway
- to work with the Macmillan evaluation team to deliver a robust evaluation with national comparisons

8.2.7   Ealing Hospital NHS Trust (NW London Cancer Network)

This pilot will support 0.6 of a Macmillan Nurse (Community Care) and 0.6 of a Macmillan Nurse (Primary Care), 0.6 of a Macmillan CCM and 1 Macmillan SW. The pilot is designed to:

- provide efficient, effective and equitable patient-centred shared care in the community for patients who have cancer and cancer aftercare needs
- develop innovative approaches to supported self-management
- evaluate the Macmillan One-to-One Support site in terms of numbers of patient episodes, places of care, primary care contribution to shared care, completed care plans, and patient/family/carer satisfaction with the system as a whole
- evaluate the four Macmillan One-to-One Support roles – number and value of patient encounters (using Macmillan's four levels of intervention), practitioner diaries for anecdotes of quality and systemic problems, primary care satisfaction with the system as a whole, patient contribution to assessing communication problems and posting Special Patient Notes

- evaluate the educational workshops and stakeholder events for their impact on learning, boundary spanning and coordinated policy
- identify lessons for systems of care for Long Term Conditions other than cancer

Existing cancer care pathway

The present cancer care pathway involves specialists only. Patients with suspected cancer are referred from general practice under the 'two week rule' (must be seen within two weeks of referral) which accounts for approximately half of all those attending. Primary care practitioners contribute to care only when asked by a patient or a specialist (except for shared care for children with Great Ormond Street).

Secondary care practitioners refer to tertiary and palliative care, but this also involves little shared care – instead, the different disciplines more or less 'take over' the care of patients.

How the envisaged pathway will look

The proposed new care pathway will involve shared care between Ealing secondary care and Ealing.

Primary/community care – the pilot One-to-One Support teams will provide the community-based care and will also facilitate the development of a shared care system that allows other primary/community care practitioners to contribute when appropriate.

In the first instance, focus will be on a) community (rather than hospital) follow up, or self-care of patients who have recovered from cancer treatment and are stratified as low risk, b) establishing a shared care process that could be adapted for patients with other long-term conditions, and c) embedding mechanisms to evaluate the cost and communication needs of shared care for cancer.

Community follow up will include innovative ways to release the potential of patients to improve their own health and contribute to health improvement of others (e.g. Health Improvement Events).

A second stage will more actively involve primary/community practitioners and will require release of funds from reduced hospital activity. It will include a) primary care contribution to case management and shared care in partnership with the One-to-One Pilot team, b) specialist support for primary care to increase local capacity to deal with cancer care and end of life care, c) inter-organisational collaboration to develop shared care processes for all Long Term Conditions.

8.2.8   Care Plus Group (Humber & Yorkshire Cancer Coast Network)

This pilot will support one Macmillan Nurse (Community Care) and one Macmillan Nurse (Primary Care), one Macmillan CCM and one Macmillan SW.

The overall aim of the pilot will be to support the patient and the family through treatment and beyond. Acting as an advocate and co-ordinating all care, the team working together will provide a health and social care support team, which will be proactive in planning care and providing health and wellbeing advice to the patient and family/carer. This will include self-care education, signposting, or self-symptom management.

The pilot roles within North East Lincolnshire will be based on the existing complex case management model which is partially established for those with multiple long term conditions or those with palliative and end of life care needs. The model works on the Five Cs:

- clinical (advanced skill and knowledge)
- care coordination
- communication
- coach
- care champion

It is this model that the team will work within.

Care Plus Group is a Health and Social Care provider committed to delivering the highest quality care closer to home. Care Plus Group is situated within North East Lincolnshire (NEL) and serves a population of 157,300. NEL is a highly deprived area, relative to other areas in the country for all of the components of deprivation, income, employment, education, crime, housing, living environment, health, etc. It has the seventh highest cancer premature mortality rate, with lung cancer accounting for the largest proportion of all cancer deaths.

For all cancers (grouped together) the survival rate has improved since 1994-98 from 39.2% to 48.7% in 2000-04 in North East Lincolnshire. However, the local survival rate is still slightly lower than the average for Yorkshire and Humber (49.5%). North East Lincolnshire has seen improvements in cost effectiveness for some health programme areas in 2009/10 compared to 2008/9, particularly for cancers. However, the area still has comparatively high spend and poorer outcomes than the national average. Within NEL, initiatives need to be explored that will improve the outcomes relating to cancer survivorship and also improve the outcomes for those already established as a cancer survivor.

8.3 Wave Two pilot sites

8.3.1 South Eastern Health and Social Care Trust (Northern Ireland) (Northern Ireland Cancer Network)

This pilot will support two Macmillan Cancer Support Workers (one WTE), and two Macmillan Nurse Community Care posts (0.5 WTE). These roles would be piloted specifically within the breast, colorectal and urology services.

The South Eastern Health and Social Care Trust (SET) is an integrated organisation, incorporating acute hospital services, community health, social services, mental health services and children's services. The Trust's geographical area is both rural and urban and extends from Bangor in the north to Newcastle in the south, from Glenavy in the west and includes the Ards Peninsula on the east. In addition to geographical spread, there is also noticeable diversity in its population characteristics embracing areas of relative prosperity as well as pockets of considerable deprivation and need. The development of cancer services is one of the Trust's top strategic objectives with clear commissioner focus on *Transforming Cancer Follow Up*.

The underpinning principles of cancer services outlined within the Strategic Cancer Plan 2008-2013 are to provide services that are:

- patient focused
- developed collaboratively in partnership with statutory and voluntary bodies including services users
- integrated and seamless to provide flexible and responsive services
- delivered within the context of the Health and Social Services strategic goals

Building on the strategic plan, the Trust is currently working towards implementation of the objectives in *Transforming your Care*, and the requirements of the Quality Improvement and Cost Reduction Programme, recently published reports following a comprehensive review of the Health Service in N Ireland. These reports recommend transformational change to improve services addressing:

- improved management of long term conditions
- the need to move to community based treatment and care with hospital outreach
- increased productivity and efficiency throughout all Trust services
- improved patient flow

The objectives of this pilot is for both roles to be closely aligned into both the acute sector MDT and primary care teams, including GPs and District Nurses supporting integrated care and a smooth transition of care from secondary to primary care with enhanced communication across all boundaries. It is anticipated that the initial focus for the support worker role would be secondary care working alongside the relevant MDT with a gradual shift to primary care.

The key objectives of the **Macmillan Support Worker** will be to:

- signpost patients to the most appropriate resource
- support patients in development of self-managed care plans
- release CNS time to provide a higher level of support to patients with increased complexity
- triage phone calls providing basic telephone advice
- co-ordinate assessments, appointments and investigations
- support the co-ordination of Health and Wellbeing Clinics
- co-ordinate education and support for people with non-complex care needs
- co-ordinate handover to other teams
- provide education and access to appropriate resources for patients and their relatives

The key objectives for the **Macmillan Nurse Community Care** will be to:

- provide proactive aftercare for people living with cancer
- receive all Treatment Record Summaries (TRS) and provide on-going holistic assessment
- proactively manage the cancer care review of patients who have completed treatment
- proactively manage on-going surveillance where appropriate such as PSA testing in urology to reduce the need for hospital review
- facilitate and enable the education of primary health care teams

8.3.2 Western Health and Social Care Trust (Northern Ireland) (Northern Ireland Cancer Network)

This pilot will support one Macmillan Complex Case Manager (0.5 WTE), one Macmillan Community Care Nurse (0.5 WTE) and one Macmillan Cancer Support Worker (1.0 WTE).

The overall aim of the pilot is to ensure that patients living with cancer are supported and educated in self-management to live with or beyond cancer, and integrate back into their community. In doing so the team will ensure "*individuals will have the opportunity to make decisions that help maintain good health and wellbeing*" (Transforming Your Care: A Review of Health & Social Care NI, January 2012).

The objectives are:

- a seamless transition for patients in their cancer journey
- supporting and signposting patients to relevant voluntary and statutory services in a timely manner
- improving co-ordination of community care and achieving a more holistic approach for patients
- to improve patient/carers experience and outcomes
- support patient choice (i.e. preferred place of care)
- reduction in re-referrals/hospital consultant appointments
- to support patients in the self-management process and reduce reliance on core services

It is proposed for the purposes of the funding that the pilot will focus on the northern sector (i.e. Londonderry and Limavady) of the Western Trust area with the main acute hospital being Altnagelvin.

The pilot will integrate into the already established NICaN cancer pathways for breast and prostate as attached. It is envisaged the pathways will be enhanced with particular reference to *Transforming Cancer Follow-up* and the pathways associated with the risk stratified model of care.

The Macmillan One-to-One Support team will identify patients with the site specific teams for breast and urology at the most appropriate point to commence the self-management model.

Whilst the current pathways attached involve diagnostic screening, assessment and treatment, the One-to-One Support team intervention will be at the point of completion of treatment. This will enable patients to embrace self-management which is currently not part of the cancer pathway.

8.3.3 Aneurin Bevan Health Board (Wales) (South Wales Cancer Network)

This pilot will include one Macmillan Community Care Nurse, two Macmillan Primary Care Nurses, one Macmillan Complex Case Manager, and one Macmillan Support Worker.

The development of the pilot bid from ABHB was led by the local Macmillan GP Facilitator, who had identified that there was a significant gap in provision for people who are living with or survive cancer after their cancer treatment has finished.

The posts will be targeted on two geographical areas in Gwent, the area ABHB covers: Caerphilly North NCN (Neighbourhood Care Network – see EOI) and Newport West NCN. Newport West NCN has a GP registered patient population of 51,306 and Caerphilly North NCN has a GP registered patient population of 66,268. Both of these areas have high levels of deprivation and higher cancer incidence rates than Wales compared as a whole.

The posts will enable the development of a robust community/primary care aftercare pathway for patients living with and beyond cancer, as well as influence the development of a seamless pathway between primary and secondary care. Specifically, the key objectives for the site are to:

- develop a seamless pathway for patients between secondary and primary care
- support development of the cancer pathway within primary care
- empower patients to self-manage and ensure that they are aware of the support available for them to access
- enable patients living with and beyond cancer to live fulfilling lives as anyone else with a long term condition
- support primary and community professionals to adopt a LTC approach to supporting cancer survivors
- engage with other organisations, particularly social services departments, to recognise and act upon the key role they play in supporting cancer survivors
- help to embed the principle of a holistic assessment and care plan for every cancer patient during treatment and clear risk stratification for discharge back to the community in the two NCN areas

8.3.4 NHS Oldham CCG led supported by Pennine Care NHS Foundation Trust (Greater Manchester and Cheshire Cancer Network)

This pilot will include one Macmillan Primary Care Nurse (0.6 WTE), one Macmillan Complex Case Manager (0.6 WTE) and one Macmillan Support Worker (1.0 WTE).

There are limited and variable cancer follow-up and aftercare services in primary and community health services in this geography, with at best 'patchy' provision of systemic cancer care reviews, survivorship models, long-term condition management and aftercare. This pilot will explore and pilot a systemic primary and community care support pathway for patients diagnosed with cancer (as well as those at risk or in fear of developing cancer). This will include the creation of a new, sustainable primary care model for providing holistic patient and family support, from cancer diagnosis, throughout treatment and into aftercare. This will be complemented by an element of lifestyle coaching to reduce the likelihood of cancer/recurrence of cancer, as well as promoting early diagnosis and screening.

It is also envisaged that a systemic long-term condition management service for cancer patients can be delivered in a cost effective way while also providing more and better quality support for people affected by cancer. It is also envisaged that this approach will make best use of existing specialist health, social care and carer support services by clearly signposting them where appropriate.

Expected outcomes and benefits include:

- primary care – increased cancer care reviews undertaken in general practice and to a higher standard
- complex case manager – appropriate cohort of patients being seen, leading to improved clinical outcomes and reduced unnecessary hospital admissions
- support worker – better engagement, better signposting, and more referrals into the appropriate setting

8.3.5   NHS Forth Valley (Scotland) (West of Scotland Cancer Network)

This site will pilot one Macmillan Community Care Nurse and two Macmillan Support Workers.

NHSFV has a detailed Healthcare Strategy covering all sectors of healthcare provision. The Cancer Board in NHSFV is a conduit between the Regional Cancer Advisory Group and regional Cancer MCNs and services in NHSFV, to ensure that patients have equitable access to care and that regional initiatives are both appropriate for the Forth Valley cancer service and implemented locally.

There are three Community Healthcare Partnerships who have an important role in delivering the cancer plan. Most patients receiving cancer treatments are provided with this on an ambulatory care basis, therefore the majority of their time is spent in primary care during treatment. Some follow-up care for patients is provided in primary care at present with scope for further extension to this.

Cancer care is currently provided by one cancer team based within the acute hospital. Chemotherapy for the majority of lung, colorectal, breast and urological, plus patients with blood cancers is provided in Forth Valley Royal Hospital. NHS Forth Valley has a population in excess of 300.000.   There are approximately 1300-1500 new cancers diagnosed yearly with approximately 800 deaths due to cancer out of 3000 per year. There is a large rural population, giving rise to more travel for people to attend follow-up appointments.

The objectives for this pilot are to:

- develop and improve the on-going support of patients living with cancer in line with a key objective of the Scottish Government: *Transforming Care After Treatment*
- introduce a holistic needs assessment at key points along the pathway and ensure every patient with a cancer diagnosis has a point of contact for support
- develop a risk stratified pathway for those patients who access the One-to-One Support service
- develop a new pathway to involve the patients meeting the named community support, either HCSW or District Nurse (DN), in the immediate post treatment period (which is identified as one of the most difficult times for cancer patients) and would be known to the patient as the point of contact from thereon, whilst the existing cancer pathway facilitates support from the CNS from diagnosis to death for most patients, there are inconsistencies and inequity between the different cancers as to how that is provided
- facilitate the community DN/HCSW to have direct access to the CNS and therefore back into the acute care service if required. The new pathway will enable NHSFV to deliver on the vision of the oncology/palliative care nursing team which focuses on equity of care

- implement the roles across a number of GP practices
- implement a triage/support line as a single point of contact for patients and carers
- maximise benefit of funding and cascade supportive ethos throughout the DN community. Through planned awareness sessions, this will aim to optimise sustainability as it will become normal day-to-day practice. They will develop a Single Point of Contact for all three CHPs developing pathways across health and social care
- deliver the service across community, primary care, acute and social services along with other non-statutory organisations such as hospice and care homes. The postholders will have the confidence and competence to deliver across all organisational and professional levels to ensure quality care
- develop a balanced scorecard specific to the role that will allow on-going collection of data to inform annual reports
- pilot the End of Treatment Summary

8.3.6 *Betsi Cadwaladr University Health Board (Wales) (North Wales Cancer Network)*

This site will pilot two Macmillan Community Care Nurses, one Macmillan Primary Care Nurse, and one Macmillan Support Worker.

These four posts will be managed by the Locality Matrons/GP Advisor/Facilitator and Matron for Cancer Services, supported by the One-to-One Project Lead and Associate Chiefs of Staff (Nursing) for Primary Care Specialist Medicine and Cancer Clinical Programme Groups (CPGs). Three of the posts will be based within the community/primary care settings and one of the posts will be based within Cancer Services; all will build upon existing relationships with Cancer CPG, urology cancer services,, acute and community specialist nursing and multidisciplinary teams and social care colleagues to develop risk stratified pathways for those accessing the One-to-One Support service.

The Macmillan Support worker will be involved with patients at level 1 working at a single site – the prostate cancer tumour site – which has been selected for the following reasons:

- MDT stability, leadership and support (Lead Clinician, Clinical Nurse Specialist (CNS) /Advanced Nurse Practitioner (ANP)/ Admin and Information Manager, Senior Macmillan Information and Support Facilitator)
- will provide an opportunity to understand need from a patient and professional perspective (information, education, communication and support) along the patient pathway
- recognition that patient needs are not being adequately addressed within the present system
- will provide an opportunity to pilot the role in the context and compare the outputs from the roles across a varied number of tumour sites including those that have site sub groupings
- will provide an opportunity to pilot the role at a single DGH recognising the geographical challenges of North Wales
- will span various Clinical Programme Groups/Departments and services, including social care
- will provide an opportunity to assess the role in the context of the CNS review currently underway across North Wales (supported by Macmillan Cancer Support)
- will provide an opportunity to assess the role in the context of the Cancer Key Worker Role

The Macmillan Nurses Community Care posts will work across a two-locality model (North Denbighshire and South Wrexham). The postholders will be involved with patients at level 2 working within existing localities and community nursing teams and identifying patients who would benefit from this type of support from the caseload.

Specifically, they will:

- support the principles which have underpinned the development of localities, specifically joined up working within local communities, delivering as much as safely possible within the local community
- provide an opportunity to assess the role in the context of the Cancer Key Worker Role

The Macmillan Nurse Primary Care will support patients at level 2 working within existing GP Practices within a single locality (South Wrexham). Specifically, this will include:

- providing an opportunity to assess the education and training needs of primary care professionals as this relates to cancer care
- providing an opportunity to assess the role in the context of the Cancer Key Worker Role

8.3.7 West Sussex - including Western Sussex Hospitals NHS Trust, Surrey and Sussex Healthcare NHS Trust and Sussex Community NHS Trust (Sussex Cancer Network)

This site will pilot two Macmillan Community Care Nurses (one WTE) and two Macmillan Support Workers (two WTE). The aim of the pilot is to build a structured approach to assessing patient needs at the end of cancer treatment, and improve links between secondary care and community services for those coping with the consequences of pelvic cancer including colorectal, urological or gynaecological cancer.

This pilot focuses on a specific area of need that has been identified through a Macmillan NCSI scoping exercise plus NHS patient experience to be an area of need for service improvement within the region. The southern region of England has a high proportion of elderly plus a mix of urban and rural localities. Nationally the numbers of those over 65 who have experienced cancer and its treatment is approximately 13% and growing yearly. In West Sussex those over 65 form 20% of the population and over 85 4.6%, this number is growing. Issues of frailty, co-morbid disease and lack of supportive family networks make this population at greater risk of adverse events and potential long term health problems.

This group of cancer survivors return to hospital services and require more primary care visits than other cancer survivors. Colorectal, prostate and gynaecological malignancies are predominantly diseases of older members of the population and cancers that have fewer clinical nurse specialists than other patient groups. Over 25% of survivors of colorectal cancer do not have good control of their bowels whilst 66% of men report sexual dysfunction at two years. In gynaecological cancer bowel problems are also common starting within the first 18 months and bladder problems occurring post treatment. A lower risk of late effects are found in non-smokers and those physically active, therefore promoting health and managing early symptoms is a key for enhancing quality of life. Care can be fragmented between urological, surgical and oncology services and providing co-ordination through the pilot would provide benefits to patients.

The proposed model and service redesign is to link these roles with existing community services such as sexual dysfunction, psychosexual counselling, continence advice, dietetics and nutritional services, falls and fracture services and exercise and support centres. However, they will also set up new clinics e.g. symptom management post radiotherapy, surgery and managing GI problems with rapid access to Acute Trust. Care will be greatly enhanced by community roles that support coping and self-management using the risk stratification process developed by the National Survivorship initiative.

Specific objectives for the pilot include to:

- test the effectiveness of implementing a screening tool for the early identification of people likely to have on-going pelvic problems and support needs after cancer treatment
- test the ability to integrate people with cancer into existing community services
- identify the staff education needs where there are service gaps
- build a base for self-management for people with cancer that is similar to those in existence for those with long term conditions
- evaluate the location for the MSW and MNCC as related to the three different characteristics of the West Sussex population (elderly, very elderly, rural vs. urban)
- build a business case for inclusion into future GP commissioning
- build the case for re-designed pathways for cancer patients, specifically with regard to follow-up and long-term management

9   Strategic Stakeholder Thematic Analysis

As part of the baseline process we interviewed 17 key strategic stakeholders from the following organisations/backgrounds:

- Macmillan
- user representatives
- representatives from the Department of Health
- senior stakeholders from the devolved nations
- Nurse Directors from Cancer Networks
- representative from Social Care Institute for Excellence

The key themes that emerged from these interviews are summarised below.

9.1   The changing cancer story

Stakeholders were clear that there is a requirement to change how cancer is treated and managed in the NHS. As more people live with cancer for longer, the current models of care will become unsustainable, a challenge that will be further exacerbated as the population ages, and improvements in awareness and early diagnosis results in more people living with and surviving cancer. The challenge for the health and social care sector will be to develop a workforce that can sustainably support the needs of people living with cancer – a move that will require more efficient ways of working, and moving care and treatment out of secondary care and into the community.

The One-to-One Support Implementation Project is directly contributing to addressing this challenge by piloting ideas about how our future cancer workforce could be shaped, and by gathering evidence from a range of perspectives (including patients, carers, clinicians in primary and secondary care, commissioners) on the extent to which this approach is fit for purpose and cost effective. Stakeholders were clear that the concept of one-to-one support has been robustly developed and is likely to represent the best approach available, and are confident that it will be a success. However, they also noted that even if the pilots are not successful, the process of evaluating their implementation, operation and the outcomes and impacts that they generate will significantly advance and inform future approaches to developing a sustainable, patient focused workforce that can effectively and efficiently support people living with cancer.

9.2   The delivery of existing policy

9.2.1   England

Stakeholders were very clear that one-to-one support was strongly aligned with existing policy in England. Stakeholders pointed to the inclusion of the commitment from Macmillan in Improving Outcomes: a strategy for cancer to invest £300m over the next seven to ten years to support the NHS to create up to 2,700 additional one-to-one support posts in England. They recognise that new models of delivery – and a remodelled workforce – are required to deliver effective better cancer care now and in the future, and regard this pilot as an exciting step in exploring the extent to which this model can contribute to cost effective whole system improvement across the NHS.

Stakeholders indicated that the national driver for the one-to-one support posts in Scotland is the ongoing debate about future workforce planning, particularly in relation to concern that resources will not be able to provide existing levels of service in as demand rises in the future. This includes significant concern about the future profile of the nursing profession in Scotland. There is currently no clear policy on what the future succession planning model for cancer in Scotland will look like beyond recognising that cancer has implications that are more closely aligned to long term conditions or management of a chronic illness.

The fact that there is little clarity on what the cancer workforce may look like in Scotland therefore offers a significant opportunity for Macmillan to influence what this looks like, through gathering learning and evidence from pilots such as this one.

9.2.3 *Wales*

The one-to-one support posts offer significant potential to enable, support and improve the delivery of existing health and social care policy in Wales. For example the Welsh Cancer Delivery plan calls for all patients to receive an assessment and care plan, ideally at diagnosis but at latest at the end of their treatment – which the new Macmillan posts are ideally placed to deliver.

In addition, the Cancer Rehabilitation Standards (announced in 2010) called for each patient diagnosed with cancer to have a nominated 'key worker' to coordinate their care for the duration of their treatment in hospital and, in recognition that people living with cancer have ongoing needs following their treatment, in primary care through their GP. While the standards called for the key worker to be the most appropriate NHS worker depending on where the patient is in their cancer treatment, they did not provide clarity on what a key worker should be. As a result Health Boards in Wales have adopted very different approaches to the identification and practices of key workers in secondary care, and the lack of clarity has led to the role not being effectively implemented post-treatment or in the community. The One-to-One Support Implementation Project posts – particularly the Macmillan Nurse Community Care, Macmillan Nurse Primary Care, and Macmillan Cancer Support Worker – offer a well designed and defined approach to addressing this requirement.

9.3   Supporting people not in active treatment

Stakeholders reported consistently that the vast majority of people affected by cancer who are not in 'active treatment' do not feel that they receive the support that they require. Specifically this includes the absence of care, ongoing support and non-clinical follow up following treatment. They also report that there is currently no consistent mechanism or approach for assessing and addressing the needs of people affected by cancer following the active phase of their treatment.

This has been reinforced by the diagnosis, treatment and follow up of cancer care largely falling under the remit and responsibility of those working in secondary care, with the result that practitioners in primary care (GPs, district nurses, health visitors, other community practitioners) have become deskilled and/or lost confidence in supporting people affected by cancer. Therefore one-to-one support offers significant scope to reintroduce care and support in the community for people affected by cancer, and an approach that focuses on ensuring that the right one-to-one support is delivered by the right person at the right time and in the right way at all phases of the cancer journey - and not just during active treatment but also when they're living long term at home.

9.4   Key drivers for successful implementation

9.4.1   Managing the interface between secondary and primary care

Stakeholders indicated that one-to-one support offers significant opportunity to improve the scope, quality and appropriateness of the care that people affected by cancer receive when they are discharged from secondary care, and to improve coordination between primary and secondary care to better support patients once they have been discharged. This will require the Macmillan postholders to build strong relationships with key stakeholders in both primary and secondary care to raise awareness of – and build confidence in – the new service amongst clinicians in secondary care.

It will also require significant levels of support from key strategic stakeholders and influencers within the organisations they are working with to encourage clinicians to change the way they work and build links with the new Macmillan services.

9.4.2   Cancer care in the community – managing a long term condition

There was a consistent view that the current culture across the NHS is that cancer is an 'acute sector' condition, and that working to overcome this culture is likely to present a significant challenge to the performance and success of the pilots. Changing this culture and perception will require patiently building relationships with key influencers and proving the value of a new approach. It is also likely to take a significant amount of time. This will present a challenge both throughout the delivery of the pilots, and for the medium-long term sustainability of this approach if these perceptions cannot be overcome.

Stakeholder reported that clinicians in primary care in general – and GPs in particular – have a vital role to play in transforming care and supporting the management of cancer as a long term condition. This will support people affected by cancer to get the ongoing treatment and support that they need, and to view it as part of their role to supporting people living with cancer as a long-term condition. The pilots can help to support this transition in two ways:

- by bridging the gap and building links between primary and secondary care, through the development and nurturing of relationships with clinicians from both sectors who are in touch with the new service
- by building the capacity – where appropriate – of existing primary care services, for example practice nurses, so they have the skills, expertise and confidence to assess the needs of and support people affected by cancer

9.4.3   Short-term sustainability and resilience

Several stakeholders noted that pilots of this nature can be particularly susceptible to the leadership abilities of one (or a small number of) individuals. Pilots are often driven by innovative individuals who have a significant level of enthusiasm for the new service, and invest energy, time and resources into its development and implementation. Crucially for this pilot, they also often develop and maintain the core relationships with senior stakeholders, clinicians and influencers that support and engage with the service. A risk for the One-to-One Support pilots is therefore that a key individual either leaves or is unable to work for a significant period of time at a pilot site, and the key leadership, knowledge, and relationships leave with them. While it is difficult to mitigate this risk, Macmillan should continue to encourage and support the pilot sites to safeguard the sustainability – and where appropriate resilience – of the new services.

9.5   Sustainability

Stakeholders were clear in their view that the pilots are very likely to improve the quality of care and patient experience –because the approach has been robustly researched and developed, but perhaps primarily because there is currently little to no consistent or coordinated support of this type for people affected by cancer. If this proves to be the case, the key question for sustainability will become the extent to which the pilots demonstrate that this approach delivers value for money. Ideally, this would include not only demonstrating that the new model saves money, but to whom within the healthcare system those savings accrue.

Several stakeholders also noted a further challenge in terms of sustainability. The new posts are very much focused on delivering patient focused support in the community. If this approach proves to be a success, along with wider demographic changes, it will require money to flow from acute to primary care - a transition that has been strongly resisted across the UK. While the short term focus remains proving that one-to-one support delivers better care and health outcomes for patients in a more cost effective manner, Macmillan needs to be aware that the bigger challenge may be in challenging the culture of how resources are distributed within the NHS.

10 Conclusions

10.1 Cancer – the evolving challenge

The cancer story in the UK is changing. If current trends continue, the number of people living with cancer will double to four million in the UK by 2030. New types of treatment will help more people to live with cancer for longer, and live beyond cancer. Improvements in survival rates are moving cancer from a 'terminal disease' to a 'chronic life threatening illness'. However, this is also likely to result in one of the more complex pathways in the NHS becoming even more difficult for patients to navigate and clinicians to effectively manage, and the significant resources that the NHS already allocate to the treatment of cancer is likely to increase.

There is also significant scope for improving survival rates for cancer in the UK; for example, if survival rates in England were to improve to match the top performers in Europe, around 10,000 lives could be saved each year.

As noted above, cancer care is often one of the more complex pathways in the NHS, and recent evidence, notably from the National Audit Office (2005) and the Picker Institute (2009), highlights the challenges patients experience in accessing follow-up care, with only half of patients in some cancer groups benefiting from such support. Those who report having the 'best' access to follow-up care, often describe 'working hard' to get it. The most common problems in accessing this support are attributed to a lack of:

- co-ordination
- local provision
- integrated and holistic care
- specialised services, either locally, or in some cases nationally

It is therefore clear that new models of care will need to be developed to deliver the quality and volume of care required in a cost effective manner consistently across the UK.

10.2 One-to-one support and long-term conditions

Currently, not all people affected by cancer have access to a CNS or a key worker. There is an emerging consensus that the effective management of complex chronic diseases represents one of the greatest challenges for healthcare systems, including the NHS. There is also a growing evidence base that this model of support has worked well for other long-term conditions, and that it can offer significant benefits to people living with and surviving cancer (most notably, the 2010 Cancer Patient Experience Survey highlighted that patients who had received support from CNSs reported having a better experience than those who did not).

The National Cancer Survivorship Initiative highlights as good practice a number elements of care that are consistent with the One-to-One Support Implementation Project, notably that the care needs of cancer patients should be assessed at key transition points across the pathway, and a plan of care adopted to reflect the resulting risk stratification based around:

- supported self-management
- shared care
- complex case management

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It is clear that the cancer workforce that will be required in future is set to grow, along with the improving rates in cancer survival, and that as care increasingly focuses on providing support from the right person with the right skills and knowledge to meet individual needs, then those needs might best be met by a specialist nurse, but equally they might be met by a District Nurse. It is therefore clear that one-to-one support offers significant potential support to the development of cancer services across the UK that adopt this approach to care, and therefore improve care for people living with and beyond cancer. The extent to which the pilot sites are able to do this in a cost effective manner will be key to the sustainability and future roll out of this approach.

10.3   Cancer care policy in the UK – does the One-to-One Support project fit?

The One-to-One Support Implementation Project aligns strongly with – and will contribute to the implementation of – healthcare policy both across the UK and in each of the four home nations. Specifically:

- all four home nations have cancer specific plans
- all four home nations also promote the following elements of care which fit well with one-to-one support:
    - a focus on early detection and awareness
    - improved information for GPs and the public
    - access to greater levels of nurse-led support

The only area of potential concern in relation to the ability of policy frameworks in the UK to support this type of activity is in Wales, where there is a lack of policy infrastructure to support or promote survivorship (the Cancer Plan only briefly mentions survivorship). The result is that survivorship is not a KPI/target (all the KPIs relating to cancer in Wales relate to reducing waiting times). While this is unlikely to directly influence the delivery of the pilot as they have worked hard to secure buy-in at executive board level, it may have a negative influence on sustainability of the roles.

While the One-to-One Support Implementation Project is consistent with cancer care policy in the UK, sustainability of the posts may still prove to be a challenge in the medium to long term given the significant pressure on resources within the UK's health and social care systems. The first step to addressing this is to ensure that the impact delivered by this model is not only robustly evidenced, but robustly evidenced from the perspective of each key stakeholder group (e.g. central and devolved government, patients, clinicians in both primary and secondary care, commissioners) – in short, proving that one-to-one support works and delivers better outcomes and impact in a cost effective way. This will enable Macmillan to continue to work to influence policy across the UK to ensure that this approach – if successful – is built into future models of health and social care (and workforce planning).

10.4   Strong stakeholder support

There is strong stakeholder support for the pilot, and stakeholders are extremely enthusiastic about the potential of the pilot to deliver a wide range of outcomes and impacts both within the health and social care systems and for patients. This level of support provides a strong foundation for the pilot, and significant levels of expertise and influence to tackle any challenges that emerge as it progresses.

This level of support also brings a degree of pressure for Macmillan and the pilots themselves. It will therefore be important to manage expectations at all levels across the lifetime of the pilot, ensuring they are in line with the projects core aims and objectives, and what can be delivered by 64 posts across 15 pilot sites.

10.5   The pilot sites

There are 16 One-to-One Support pilot sites across the UK, 15 of which will be included within this evaluation. The evaluation pilot sites provide good coverage across the UK, with ten in England, two in Wales, two in Northern Ireland and one in Scotland.

It is clear that the proposed approach and aims and objectives highlighted by the sites align strongly with Macmillan's anticipated outcomes for the pilot programme as they are defined in the programme logic model. While it is too early to tell if some of these outcomes will be met (for example the extent to which the roles are accepted by peers and seen as credible and as complimentary to existing roles), the early indicators are positive, specifically in relation to:

- proposing to make changes to the care pathway that provide more joined up services that better meet the needs of people living with and beyond cancer
- maintaining a focus on improving the quality of care and patient experience
- improving clinical outcomes
- improving productivity

10.6   Early themes emerging from the pilot sites

There are a number of themes that emerged from our early consultations with the pilot sites that may have an impact on both the short and long-term performance of the One-to-One Support mechanism particularly in relation to:

- stakeholder engagement key for success: the success of the pilots will be strongly influenced by the ability of pilot leads and postholders to secure the support of key influencers – both within their own organisation and across the wider healthcare system. Buy-in from clinical staff will be crucial – particularly in relation to primary care professionals who will have a significant impact on the pilots, but have traditionally been less involved with cancer treatment

- recruitment: the quality of applications received by the pilot posts to date has been mixed. While some report that they were extremely pleased with the volume and quality of applications they have received, others have experienced difficulty in recruiting the calibre of staff with the skills they require. Particular barriers include the fixed term nature of the posts (with potential candidates particularly concerned about what posts would be available for them at the end of the period, given the current uncertainty within the NHS), or local HR processes that were inhibiting the recruitment process. There is also an association amongst many applicants of the Macmillan brand having strong links to palliative care, with the result that candidates who present for interview have the wrong idea about the aims of these posts. Where this has occurred, sites have re-advertised the posts with a strong emphasis on highlighting that these posts will provide support to people living with or beyond cancer. Some of this could be mitigated in the future by ensuring that the sites are very explicit and clear in the recruitment advertisement that the posts are not palliative – an area where Macmillan could potentially help by highlighting this as an issue for any future sites and providing some carefully designed text that describes what the posts are to be included in any future advertisement. It will be important for the evaluation to continue to track the quality of applicant that is recruited to these posts as the recruitment process continues, and factor this into our analysis of how the pilots perform

- training and education: the requirement for a strong training and induction process has been highlighted across the sites. While specific elements of the training and induction processes vary by site, all are consistent in terms of focusing on enabling the postholders to build strong relationships with key local stakeholders. Some pilots are planning to supplement this with Macmillan support for the postholders – for example the introduction to cancer course – and Macmillan should consider focusing support to the sites on highlighting the range of development support they can offer to maximise the impact of the new roles

- anticipated outcomes and impact: pilot leads' articulation of the expected outcomes from, and impact of their projects, maps very well to the logic model for the programme. A key overriding theme was an expectation that the new model will deliver seamless and holistic care. Specifically:
    - in relation to patient experience and outcomes, there was strong coverage across the pilots in terms of expected outcomes on:
        - improved satisfaction
        - single point of contact
        - better information
        - better signposting
        - proactive patient management
        - less isolation
        - support for self-management
    - in relation to clinical outcomes:
        - improved quality of life
        - to a lesser extent, better awareness of the signs of recurrence
        - improving knowledge amongst primary care professionals
        - providing more services that better meet patients' needs through primary care in community settings
    - in relation to improved productivity:
        - more cost-effective skill mixing, freeing up CNS time to focus on more complex cases
        - reducing unnecessary admissions
        - reducing unnecessary GP visits
        - reducing unnecessary outpatient follow-ups

Each of these factors will be closely monitored throughout the evaluation, as we work closely with the pilot sites to quantify and evidence the impact that one-to-one support delivers.

Frontline
November 2012

Cancer Baseline by Home Nation

This section presents the current state of cancer in each of the home nations using the most up-to-date available information. While it would be ideal to compare the performance of each plot site (and the cohort as a whole) with these baselines, there is often a substantial lag in the generation of this data. The statistics presented below do present an overview of the most up to date picture in each home nation, and many of the trends will be common across all 4 countries in the United Kingdom.

This baseline is also important as the Frontier Economics report[50] makes reference to the potential impact that one-to-one support for cancer patients may have on recurrence and survival rates, citing 'potential reduction in recurrence of some cancers as a result of healthier life-style encouraged by CNSs / Care Coordinators'. There is swathe of literature that tentatively links increased levels of physical activity with improved survival rates for cancer[51] and tailored, patient specific, support may result in a greater number of patients using exercise to supplement their recovery. The influence of CNSs and the one-to-one support they provide has been widely reported and is summarised by The Royal College of Nursing:

> *"[CNSs] provide direct patient care and can play a vital role in educating patients on how best to manage their symptoms, as well as offering support following diagnosis. In many cases the involvement of a specialist nurse can prevent patients being re-hospitalised". (Royal College of Nursing[52], 2010)*

We discuss each nation in turn, examining the existing cancer statistics that exist for each. The statistics may vary in terms of trend analysis as some of the home nations have been publicly reporting on cancer for a longer period of time than others. The headline statistics are displayed cumulatively at the end of this section to illustrate the changing story of cancer - that death rates are not the big issue, rather the numbers of people living with and beyond cancer and the growing numbers of people diagnosed with cancer each year in the UK.

England

Cancer incidence

Over 250,000 people in England are diagnosed with cancer every year and around 130,000 die from the disease. Currently, about 1.8 million people are living with and beyond a cancer diagnosis. The number of cancer registrations in England has been steadily increasing over time. Like the rest of the UK, this is partly due to advances in cancer detection and diagnosis, but it is also due to lifestyle influences such as increasing rates of obesity, inactivity and poor diet. Again, like the rest of the UK, England has worked to better educate the public in terms of risks of cancers and campaigns have been launched to help people to recognise the symptoms of cancers earlier.

With advances in medicine and better information sharing to encourage early detection, cancer survival rates in England have been steadily increasing for most cancers. The 4 most common cancer sites in England (and the rest of the UK) are colorectal, breast, prostate and lung.

The incidence of colorectal cancer is substantially lower in males compared with the three other UK countries, with incidence rates ranging from 57 per 100,000 in England to 68 per 100,000 in Scotland; colorectal cancer incidence is also lowest in females in England, though the differences between the countries are not substantial (rates ranging from 38 per 100,000 in England to 45 per 100,000 in Scotland). Other sites where incidence rates are lower in England include lung cancer in males and cervical cancer in women. Very few cancers have particularly high incidence rates in England in comparison with the rest of the UK.

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[50] One-to-One Support for Cancer Patients, December 2010
[51] See, for example: Holmes et al (2009); Slattery (2004); McTiernan [ed] (2006)
[52] Specialist Nurses: Changing Lives, Saving Money

Cancer prevalence rates are very useful from a policy perspective as they show how many people previously diagnosed with cancer are alive on a specified date (in this case 31st December 2006). This gives an indication of the burden of cancer on the NHS in England and helps policy makers to understand the resource implications more accurately. 1 and 5 year prevalence rates are shown in the tables included below and are split by Cancer Network area.

Figure 1: 1 year cancer prevalence by Cancer Network, England 31st December 2006

Cancer Network	Males No. of Patients	Crude proportion	ASP*	95% confidence interval		Females No. of Patients	Crude proportion	ASP*	95% confidence interval		Persons No. of Patients	Crude proportion	ASP*	95% confidence interval	
N01 Lancashire and South Cumbria	2,643	355.3	284.3	273.3 -	295.2	2,652	343.3	266.2	255.5 -	276.9	5,295	349.2	270.7	263.2 -	278.3
N02 Greater Manchester and Cheshire	5,214	348.0	310.4	302.0 -	318.9	5,261	341.5	287.1	279.0 -	295.1	10,475	344.7	293.8	288.0 -	299.5
N03 Merseyside & Cheshire	3,236	333.0	272.9	263.4 -	282.4	3,303	317.5	250.0	241.0 -	258.9	6,539	325.0	257.5	251.1 -	264.0
N06 Yorkshire Cancer Network	4,213	323.1	288.0	279.3 -	296.8	4,300	316.9	263.4	255.2 -	271.7	8,513	320.0	271.2	265.3 -	277.1
N07 Humber & Yorkshire Coast	1,927	370.3	282.9	270.0 -	295.7	1,850	344.7	259.5	246.9 -	272.0	3,777	357.3	267.4	258.6 -	276.3
N08 North Trent	2,845	324.6	263.5	253.7 -	273.4	3,178	352.0	274.6	264.5 -	284.6	6,023	338.5	265.5	258.5 -	272.4
N11 Pan Birmingham	2,898	310.5	281.8	271.4 -	292.2	2,780	285.4	247.0	237.4 -	256.7	5,678	297.7	260.4	253.4 -	267.4
N12 Arden	1,487	300.9	256.6	243.4 -	269.7	1,438	286.9	227.8	215.5 -	240.2	2,925	293.9	239.8	230.9 -	248.8
N20 Mount Vernon	1,684	275.2	242.5	230.8 -	254.2	1,939	306.1	252.7	240.9 -	264.4	3,623	290.9	245.0	236.8 -	253.2
N21 West London	2,004	218.3	235.8	225.3 -	246.2	2,163	234.0	228.9	219.0 -	238.8	4,167	226.2	229.5	222.4 -	236.6
N22 North London	1,928	257.0	275.1	262.7 -	287.5	1,771	227.9	217.3	206.8 -	227.8	3,699	242.2	241.6	233.6 -	249.5
N23 North East London	1,678	219.1	251.2	239.0 -	263.4	1,768	227.2	231.0	219.8 -	242.2	3,446	223.2	238.1	229.9 -	246.3
N24 South East London	2,028	266.3	295.8	282.7 -	308.9	2,071	266.0	256.4	244.9 -	267.9	4,099	266.1	271.5	262.9 -	280.0
N25 South West London	2,114	275.7	281.4	269.3 -	293.6	2,287	285.2	259.1	248.0 -	270.2	4,401	280.6	267.2	259.1 -	275.3
N26 Peninsula	3,247	404.9	282.7	272.6 -	292.8	3,427	404.8	283.6	273.4 -	293.9	6,674	404.9	280.1	272.9 -	287.2
N27 Dorset	1,632	481.1	314.7	298.6 -	330.8	1,575	435.2	297.3	281.1 -	313.5	3,207	457.4	301.9	290.6 -	313.3
N28 Avon, Somerset & Wiltshire	3,302	354.5	285.6	275.7 -	295.5	3,345	347.5	270.5	260.9 -	280.2	6,647	351.0	274.8	267.9 -	281.6
N29 3 Counties	1,884	369.6	274.7	262.0 -	287.4	1,883	355.1	260.8	248.3 -	273.3	3,767	362.2	264.6	255.8 -	273.4
N30 Thames Valley	3,683	316.3	293.9	284.3 -	303.4	3,859	326.4	284.2	275.0 -	293.4	7,542	321.4	285.5	279.0 -	292.1
N31 Central South Coast	3,309	345.3	269.7	260.3 -	279.1	3,544	354.0	268.2	258.8 -	277.5	6,853	349.7	266.4	259.8 -	273.0
N32 Surrey, West Sussex & Hampshire	1,781	302.3	260.2	247.9 -	272.4	1,815	295.3	241.3	229.7 -	252.9	3,596	298.7	247.1	238.7 -	255.4
N33 Sussex	1,894	339.9	241.0	229.7 -	252.3	2,005	332.6	233.7	222.5 -	244.9	3,899	336.1	233.9	226.0 -	241.8
N34 Kent & Medway	2,609	328.3	267.3	256.9 -	277.7	2,632	331.4	243.0	233.3 -	252.8	5,241	320.6	252.5	245.4 -	259.6
N35 Greater Midlands	3,030	326.5	255.3	246.1 -	264.5	3,219	336.2	257.9	248.5 -	267.2	6,249	331.4	253.2	246.7 -	259.7
N36 North of England	5,162	351.3	280.7	273.0 -	288.5	5,334	346.7	266.1	258.6 -	273.6	10,496	349.4	269.3	264.0 -	274.6
N37 Anglia	5,300	399.7	302.8	294.5 -	311.1	5,306	388.6	289.9	281.7 -	298.2	10,606	394.1	292.8	287.0 -	298.6
N38 Essex	2,444	359.1	282.3	270.9 -	293.7	2,672	373.9	280.9	269.6 -	292.1	5,116	366.7	277.7	269.8 -	285.6
N39 East Midlands	6,589	336.1	277.1	270.3 -	283.9	6,761	337.4	271.5	264.7 -	278.2	13,350	336.8	270.8	266.1 -	275.6
England¹	81,766	328.0	277.4	275.5 -	279.3	84,139	325.7	262.4	260.5 -	264.3	165,905	326.8	266.3	265.0 -	267.6

Source: NCIN

The number of people in England who were diagnosed with cancer and were still alive a year later – i.e. living with cancer (end December 2006) was 165,905 or 0.327% of the whole population of England. Prevalence is reasonably similar across men and women. Commentary around those cancer sites with highest levels of prevalence is skewed due to the varying incidence across cancer sites – i.e. there is greatest prevalence amongst the most commonly occurring cancers.

Figure 2: 5 year cancer prevalence by Cancer Network, England 31st December 2006

Cancer Network	Males No. of Patients	Crude proportion	ASP*	95% confidence interval		Females No. of Patients	Crude proportion	ASP*	95% confidence interval		Persons No. of Patients	Crude proportion	ASP*	95% confidence interval	
N01 Lancashire and South Cumbria	9,175	1233.3	979.4	959.4 -	999.5	9,729	1259.4	979.6	959.2 -	999.9	18,904	1246.6	961.7	947.6 -	975.7
N02 Greater Manchester and Cheshire	16,678	1113.1	987.2	972.3 -	1002.1	18,416	1195.5	1012.1	997.0 -	1027.1	35,094	1154.9	983.0	972.6 -	993.4
N03 Merseyside & Cheshire	11,130	1145.5	933.4	916.1 -	950.8	12,670	1217.9	970.6	953.1 -	988.0	23,800	1182.9	939.3	927.1 -	951.5
N06 Yorkshire Cancer Network	15,079	1156.0	1020.8	1004.6 -	1037.0	16,918	1246.8	1051.4	1035.1 -	1067.8	31,997	1202.6	1019.8	1008.4 -	1031.1
N07 Humber & Yorkshire Coast	6,526	1254.0	948.2	925.0 -	971.3	7,229	1347.0	1019.9	995.3 -	1044.4	13,755	1301.2	969.8	953.1 -	986.5
N08 North Trent	9,468	1080.2	878.4	860.6 -	896.1	11,322	1254.1	994.0	975.0 -	1013.0	20,790	1168.4	925.2	912.3 -	938.0
N11 Pan Birmingham	10,426	1117.0	1004.7	985.4 -	1023.9	10,729	1101.4	965.2	946.2 -	984.1	21,155	1109.0	968.5	955.2 -	981.9
N12 Arden	5,527	1118.5	930.0	906.3 -	954.5	5,962	1189.6	963.0	937.7 -	988.3	11,489	1154.3	933.1	915.7 -	950.5
N20 Mount Vernon	5,613	917.2	808.6	787.4 -	829.8	6,822	1077.0	911.4	889.0 -	933.7	12,435	998.5	850.6	835.3 -	865.8
N21 West London	7,429	809.3	871.1	851.2 -	890.9	8,508	920.4	902.3	882.7 -	921.8	15,937	865.1	878.0	864.2 -	891.8
N22 North London	6,965	928.5	976.4	953.5 -	999.3	7,234	930.8	902.6	881.3 -	923.9	14,199	929.7	923.7	908.3 -	939.2
N23 North East London	5,837	762.1	856.3	834.2 -	878.3	6,599	848.1	863.7	842.2 -	885.2	12,436	805.4	847.7	832.5 -	862.8
N24 South East London	6,699	879.6	964.4	941.2 -	987.6	7,854	1008.9	990.0	967.5 -	1012.5	14,553	944.9	964.5	948.6 -	980.5
N25 South West London	7,877	1027.5	1031.2	1008.5 -	1054.0	8,810	1098.5	1010.7	989.0 -	1032.5	16,687	1063.8	1007.5	991.9 -	1023.1
N26 Peninsula	11,300	1409.2	975.0	956.6 -	993.5	12,954	1530.1	1073.3	1053.6 -	1093.1	24,254	1471.3	1014.6	1001.2 -	1028.1
N27 Dorset	6,274	1849.6	1181.7	1151.1 -	1212.2	5,886	1626.6	1083.6	1053.2 -	1113.9	12,160	1734.5	1115.6	1094.3 -	1137.0
N28 Avon, Somerset & Wiltshire	11,775	1264.2	1011.0	992.6 -	1029.4	13,142	1365.3	1043.4	1023.6 -	1063.1	24,917	1315.6	1026.2	1013.1 -	1039.3
N29 3 Counties	6,423	1260.0	923.8	901.0 -	946.7	7,214	1360.3	1000.9	976.6 -	1025.1	13,637	1311.1	950.8	934.3 -	967.4
N30 Thames Valley	13,476	1157.5	1069.7	1051.8 -	1087.6	14,957	1365.9	1119.8	1098.7 -	1125.9	28,433	1211.7	1075.4	1062.8 -	1088.0
N31 Central South Coast	12,194	1272.3	980.9	963.2 -	998.5	13,454	1343.9	1024.4	1006.2 -	1042.6	25,648	1308.9	991.5	978.9 -	1004.1
N32 Surrey, West Sussex & Hampshire	5,854	993.7	856.7	834.7 -	878.7	6,994	1138.0	939.1	916.4 -	961.9	12,848	1067.4	889.3	873.6 -	905.0
N33 Sussex	6,432	1154.4	825.2	804.4 -	846.0	7,652	1269.3	897.7	875.9 -	919.5	14,084	1214.1	852.9	838.0 -	867.9
N34 Kent & Medway	8,649	1088.2	878.5	860.0 -	897.1	9,847	1172.5	926.2	907.2 -	945.2	18,496	1131.5	893.7	880.5 -	906.9
N35 Greater Midlands	10,533	1135.0	883.4	866.5 -	900.3	12,248	1279.3	984.1	966.0 -	1002.2	22,781	1208.3	922.1	909.8 -	934.4
N36 North of England	17,869	1216.2	966.4	952.2 -	980.6	20,343	1325.7	1027.0	1012.5 -	1041.8	38,212	1272.2	982.9	972.8 -	993.0
N37 Anglia	17,836	1345.2	1013.4	998.4 -	1028.4	19,278	1412.0	1063.5	1047.8 -	1079.1	37,114	1379.1	1026.3	1015.5 -	1037.0
N38 Essex	7,966	1170.6	917.5	897.3 -	937.8	9,191	1286.2	982.4	961.4 -	1003.4	17,157	1229.8	938.0	923.5 -	952.4
N39 East Midlands	21,418	1092.7	896.7	884.7 -	908.8	24,552	1225.1	990.9	978.1 -	1003.7	45,970	1159.6	933.1	924.3 -	941.8
England¹	282,516	1133.4	951.0	947.5 -	954.5	316,574	1225.3	997.0	993.4 -	1000.6	599,090	1180.2	961.5	959.0 -	964.0

Source: NCIN

The number of people diagnosed with cancer in England and still alive 5 years later (at the end of December 2006) was 599,090 or 1.2% of the total English population. Of this total, 47% were male and 53% female.

Cancer mortality

On average, there were 127,110 deaths a year in England (2007-2009) due to cancer. The most dominant cancer was lung cancer which killed 27,801 people, followed by colorectal, breast, prostate and pancreatic cancers. The mortality rate for England is below the UK average (174.5 in comparison with 178 per 100,000 of the population).

Cancer survival

Survival rates are now reasonably positive for prostate and breast cancer patients with 5 year survival rates over 80%. Lung cancer remains a problem and survival rates (1 and 5 years) are low (30% and less than 10% respectively).

Five-year survival was 80 per cent or higher for five malignancies (testis, melanoma of skin, breast, Hodgkin's lymphoma and prostate) and less than 20 per cent for cancers of the oesophagus, stomach, pancreas, lung and brain.

Women had higher five-year survival rates than men for most cancers, although women with bladder cancer had lower survival than men (50.2 per cent compared to 58.2 per cent).

The highest five-year survival for men was for testicular cancer, at 97.2 per cent, and in women, for malignant melanoma of the skin, at 91.6 per cent. The lowest five-year survival was for men and women diagnosed with pancreatic cancer, at 3.6 per cent and 3.8 per cent, respectively. Patients diagnosed with pancreatic cancer also had the lowest five-year survival in 2004-2008.

The most commonly diagnosed cancer in women was breast cancer, for which five-year survival was 85.1 per cent, slightly higher than for women diagnosed in 2004-2008. The most common cancer for men was prostate cancer, for which five-year survival was 81.4 per cent, slightly higher than for men diagnosed in 2004-2008.

For most cancers, five-year survival is generally lower among the oldest patients. The main and well-known exceptions are for breast cancer in women and for prostate cancer[53].

Wales

Cancer incidence

Cancer registrations in Wales have been fairly consistent over the past 4 years. Detailed information spanning a longer period is not freely available. Registration rates per 100,000 people are higher in Wales than in England, reaching 628.5 in 2010, in comparison with 529.4 in England.

Like England, and the rest of the UK, the most common cancer sites are colorectal, lung, prostate and female breast. These have substantially higher rates of incidence than any of the other cancer sites, with the exception of non-malignant skin cancer (which is excluded from the statistics so that results are not skewed).

The incidence rates for nearly all cancers in Wales show no significant differences in comparison with the three other UK countries. Cancers with the highest rates include leukaemia in males (with rates ranging from 11 per 100,000 in Northern Ireland to 15 per 100,000 in Wales) and ovarian (rates ranging from 16 per 100,000 in Northern Ireland to 19 per 100,000 in Wales).

Cancer survival

Cancer survival data for Wales is similar to that for England with the exception that Wales underperforms England in terms of its 5 year survival rates. It also lags in its 1 and 5 year survival rates for cancers specific to women (breast, ovarian and cervical). This may be due to less success in early screening or insufficient levels of longer-term support for cancer survivors, for instance.

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[53] Commentary taken from ONS

The impact of One-to-One Support will be monitored to note any effect in potentially improving these figures for Wales and for the UK as a whole.

Cancer prevalence

For both Welsh men and women, the number of people 'living with cancer' is highest in lung and colorectal sites. Marginally more men than women are living 10-20 years beyond diagnosis with lung cancer but this is a national trend across the UK as historically there had been a higher disposition among men to smoke.

Scotland

Much of the data for Scotland is extracted from the Information Services Division (ISD) of NHS Scotland. The latest statistics were compiled in April 2012 and are due to be updated again in October.

Cancer incidence

In 2010, 14,000 men and 15,400 women were diagnosed with cancer. Rates of diagnosis of cancer in Scotland have risen over the last 10 years.

For men, the most common cancers are prostate, lung and colorectal, accounting for just over half of all diagnoses (52%). For women, the most common cancers are breast, lung and colorectal, accounting for 56% of all diagnoses. Lung cancer rates most prominent across men and women combined with 4,800 cases diagnosed in 2010. This is in line with the trend across the rest of the UK.

The high prevalence of smoking in Scotland (25%, compared with 20% in England) means that smoking-related cancers have particularly high incidence rates. Lung cancer incidence is significantly higher in Scotland in comparison with the rest of the UK, with incidence rates in males ranging from 56 per 100,000 in England to 81 per 100,000 in Scotland, and in females from 38 per 100,000 in England to 57 per 100,000 in Scotland. Oral cancer incidence is also significantly higher in Scottish men, with incidence rates ranging from 11 per 100,000 in England to 17 per 100,000 in Scotland.

The incidence of malignant melanoma is highest in males and females living in Scotland in comparison with the rest of the UK (though the incidence rates are not significantly higher). A survey of children and young people found that Scotland has the highest percentage of young sunbed users in Great Britain (almost 14%).

Prostate cancer has a significantly lower incidence rate in Scotland in comparison with the three other UK countries, with rates ranging from 87 per 100,000 in Scotland to 114 per 100,000 in Northern Ireland. Some of this variation may be explained by differences in the availability and uptake of prostate-specific antigen (PSA) testing across the UK.

While many of the changes reported show a fall in the incidence of cancer types, there has been a marked increase in the rate of malignant melanoma of the skin (up by 66% in males and 60% in females). The overall fall in lung cancer rates is masking a rise in the incidence of female lung cancer (up 17%) with the 15% fall in the cancer amongst men. The reported fall in bladder cancer is due to a Europe-wide change in classification for reporting so should be viewed with some caution. Incidence rates have fallen significantly over the past 10 years for stomach cancer, cancer of the larynx, ovarian cancer and leukaemia.

Cancer prevalence

2.5% of men and 3.4% of women living in Scotland live with cancer. Of these people, 64% of the men and 55% of the women are aged over 65.

Cancer Mortality

Over 15,200 people died of cancer in Scotland in 2010. Cancer mortality rates are falling and over the last decade have decreased by 15% for men and 7% for women. The most common causes of death included lung, colorectal, breast and prostate cancers.

Cancer survival

Survival rates in Scotland have increased markedly over the last twenty years. 59% of males and 66% of females now survive for at least a year post diagnosis and 36% of men and 45% of females survive at least 5 years. Survival tends to be better for those patients who present early or have attended screening sessions. Survival after prostate cancer has improved (56% to 85%) over the last twenty years as has breast cancer (61% to 81%). Survival rates remain poor for those suffering with lung or pancreatic cancers. Liver cancer survival rates are not available for Scotland.

Northern Ireland

In 2009, 6,109 men and 5,661 women were diagnosed with cancer in Northern Ireland. Cancer was responsible for almost one quarter of deaths in Northern Ireland between 2000 and 2004 (NICR 2007)

Cancer incidence

The incidence of non-Hodgkin's lymphoma is significantly higher in Northern Ireland in comparison with the rest of the UK, with incidence rates in males ranging from 16 per 100,000 in Wales to 27 per 100,000 in Northern Ireland, and rates in females ranging from 12 per 100,000 in Wales to 22 per 100,000 in Northern Ireland. In situ cervical tumours also have significantly higher incidence rates in Northern Ireland in comparison with the three other UK countries.

The incidence of breast cancer has been lowest in Northern Ireland compared with the three other UK countries for almost two decades with rates in 2009 ranging from 119 per 100,000 in Northern Ireland to 127 per 100,000 in Scotland[54].

Non melanoma skin cancer accounted for almost a quarter of all cancer diagnoses for men and women between 1993 and 2004. Otherwise, the most prevalent cancers in men in Northern Ireland were prostate, lung and colorectal and for women breast, colorectal and lung. The prevalence of cancer increases as the population ages – the median age for diagnoses in males was 70 and in females, 68.

Cancer mortality

Deaths among females in Northern Ireland remain significantly higher than that of males. Lung cancer was the most common cause of death in men and breast cancer the most common in women.

Cancer survival

Survival rates[55] tend to be better in women with 51.2% of women surviving 5 years after diagnosis in comparison to only 39.4% of men. Survival rates have been steadily increasing for both sexes. Survival varies significantly with tumour type with 90% (5 year survival) for testicular cancer and melanoma to less than 15% (1 year survival) for pancreatic and liver cancer. Northern Ireland underperforms in terms of male survival when compared with Europe and other UK nations but fares favourably in comparison with Scotland for female survival rates. Thyroid cancer survival rates are not available for Northern Ireland.

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[54] Commentary taken from Cancer Research UK
[55] Data on survival taken from: "Survival of Cancer Patients in Northern Ireland: 1993-2004"; Northern Ireland Cancer Registry, 2007

Project One-to-One Support – pilot projects

Pilot site profile	
Organisation(s)	Aneurin Bevan Health Board Valindre Cancer Centre Cwm Taf Health Board Caerphilly County Borough Council
Location	Caerphilly North NCN and Newport West NCN – Gwent has 12 GP clusters, but have chosen to pilot this approach in these two contrasting locales (one is urban, with a high BME population and a mix of affluent and deprived areas, the other is rural with GP practices covering small populations, and a mainly white socio-economic demographic).
Cancer network(s)	South Wales Cancer Network
Pilot lead(s)	Helen Dodoo Clifford Jones
Posts	1 Complex Case Manager 1 Community Care Nurse 2 Primary Care Nurse 1 Cancer Support Worker They have applied for all four levels of support because this pilot offers a new way of working, and there is no existing infrastructure for cancer services in the community.
Tumour sites covered	Breast and Prostate – they have chosen to focus on these areas as they have the highest survivorship rate, and are recognised by GPs as a group of patients with distinct needs who are discharged from secondary care at a comparatively early stage. It is also a group that would benefit from this support, for example body image and sexuality issues, for which there is currently no support and is not something that healthcare professionals routinely consider.
Context and rationale	The local Macmillan GP facilitators, through their work programme, identified cancer survivorship as a big issue/gap within local Primary Care. Specifically, cancer survivors who did look for support were being referred to palliative care services.
Proposed service model	In the new cancer pathway: • Patients will have a holistic care assessment, have an agreed care plan and be risk stratified prior to transition to their aftercare pathway • Patients who have been treated outside of Gwent will be supported by ABHB staff once their treatment pathway has finished • Resources will be used more effectively with patients more confident in managing their own care and not requiring routine follow up appointments or needing to see their GP as frequently • Patients will be able to name their key worker • Primary and community staff will recognise and acknowledge cancer as a LTC, but will also know when to fast track patients back into secondary care services The workforce models will help us achieve this b: supporting all roles adopting a LTC approach.
Key objectives	Our key objectives are to: • Develop a seamless pathway for patients between secondary and primary care

	• Support development of the cancer pathway within primary care • Empower patients to self-manage and ensure that they are aware of the support available for them to access • Enable patients living with and beyond cancer to live fulfilling lives as anyone else with a long term condition • Support primary and community professionals to adopt a LTC approach to supporting cancer survivors • Engage with other organisations, particularly Social Services Departments, to recognise and act upon the key role they play in supporting cancer survivors • Help to embed the principle of a holistic assessment and care plan for every cancer patient during treatment and clear risk stratification for discharge back to the community in the 2 NCN areas
Fit with existing services	It is difficult to predict what the impact on the caner pathway will be, but it is envisioned that: • There will be an increase in confidence and skills of primary care staff to identify and address survivorship issues • Reduce demand for secondary care and GP appointments to address survivorship issues that could be addressed in the community • Change in ethos/culture amongst primary care professionals about treating survivorship issues in the community
Expected outcomes/benefits	• Achieving a cultural shift amongst all healthcare professionals to enable them to consider cancer as a chronic/long term condition • Increase the profile of survivorship issues, and move away from the idea that survivorship is a specialist area where patients needs can only be addressed by a specialist – thereby empowering all primary healthcare professionals to identify and address survivorship • Pilot and create a sustainable community service for patients who live with/survive cancer
Project management resource input	Cliff – Macmillan GP – 1 day per week so far, hopes this will reduce when service is up and running Helen – senior manager – intensive, but adopts as part of day job.
Potential confounding factors	The single biggest issue facing the pilot is that there is no policy infrastructure to support or promote survivorship in Wales (the Cancer Plan only briefly mentions survivorship). The result is that survivorship is not a KPI/target (all the KPIs relating to cancer in Wales relate to reducing waiting times). While this is unlikely to directly influence the delivery of the pilot as they have worked hard to secure buy in at executive board level, it may have a negative influence on sustainability of the roles. They have also faced strong resistance from local stakeholders, including district nurses and local hospices, who perceive the new roles as a threat to their existing work. The pilot leads have been working extremely hard with local stakeholders to communicate the message that the new posts will not replace existing roles.

Pilot site profile	
Organisation(s)	Berkshire Healthcare NHS Foundation Trust Heatherwood and Wexham Park NHS Foundation Trust
Location	Berkshire
Cancer network(s)	Thames Valley Cancer Network
Pilot lead(s)	Rosemary Martin
Posts	0.6 WTE Macmillan Complex Case Manager 1 Macmillan Support Worker
Tumour sites covered	Breast, Prostate, Bowel, head and neck, upper GI – Breast, Prostate, and Bowel were chosen because they have the highest cure rate, and therefore generate the biggest demand for long term support. Head and neck and upper GI were added because there is a long period of potential recurrence, and therefore are likely to benefit more from better awareness about recurrence and early presentation
Context and rationale	They decided to apply to be a pilot site because: • their Foundation Trust is committed to treating and supporting people in the community, and where possible keeping them out of hospital • recognise that currently, people living with cancer do not receive any support following completion of their treatment They were told by their Cancer Network director that they were only allowed to apply for two posts. As a result, they have limited the geography that the service will cover to one of their three Clinical Commissioning Group areas. They subsequently found out that they could have applied for more posts, and if they had been able to do so they would have been able to cover a wider geography.
Proposed service model	These roles will be developed within the Slough locality but may extend to the wider area of East Berkshire once the care pathways have been established and a level of the demand verses capacity determined. Slough locality has many challenges including; areas of deprivation, a multi-cultural population, poor quality and overcrowded houses, general ill health, several single handed / small GP practices and cancer patients receiving treatment from multiple cancer centres including London hospitals. This leads to a complex cancer pathway with patients often uncertain how to access local support. The role of CCM will be pivotal to addressing these unmet needs. Through collaboratively working with the local cancer teams, to establish a robust end of cancer treatment pathway, building on the principles of an identified key worker, who patients feel is available and knowledgeable regarding their needs, and ensuring a seamless transfer of care from hospital focused care to community care. The MSW role will work in close conjunction with the CCM providing telephone support for those patients with less clinical /complex needs and acting as a resource to signpost patients to local support and sources of information. The BHFT pilot will have 2 phases: 1. Development of a robust community focussed after treatment pathway in conjunction with HWPH Cancer Team and establishing links with other local Cancer Centres.

This will identify the patients who have completed their treatment, develop an individualised patient agreed holistic and supportive care plan and the transfer of their care to the community. As part of this pathway development a benchmarking exercise to ascertain the current number of outpatient appointments, GP visits and patient experiences will be undertaken. This will inform the sustainability plan and identify the costs associated with the current pathway.

2. Development of the processes to provide on-going support to patients by the CCM and MSW.

This will involve development of a risk stratification tool based on knowledge of the disease, effects and consequences of the cancer treatment, and individual patient factors e.g. existing co-morbidities. Throughout the project the CCM will work closely with East Berkshire PCT and Slough Clinical Commissioning Group (CCG) to ensure engagement with the GPs and routes of referrals between GPs and the CCM/MSW team.

Following the aftercare pathway development the CCM in conjunction with the MSW will identify a caseload of patients requiring on-going support. A 3 level model of aftercare support will be provided by these 2 roles

Self-care with support – NCSI suggest that between 70- 40% of patients will fall into this category. As part of the aftercare plan patients will be given information about self-management, local support groups and other types of support available locally. The patient will also be aware of any signs and symptoms to look out for and who to contact if they have any concerns. These patients will have open access to the SW/CCM as an initial point of contact.

Shared Care – NSCI suggest that 30-10% of patients will fall into this category of supportive care. On-going support is required which will be overseen by the CCM, patients will continue to have face to face, phone or email contact with professionals as part of continuing follow up. The CCM will determine who is best placed to provide this on-going support with the SW providing the less complex support.

Complex Case Management – NCSI suggest that between 35 -20% of patients fall into this category where patients are given intensive support to manage their cancer and/or other conditions. This will be provided by the CCM role in conjunction with the tumour site MDT/ relevant professionals.

Cancer patients will be treated depending which approach is most suitable, and the level of professional care will vary accordingly. Cancer survivors may move between these different options depending on their disease, health status and individual needs. The proportion of people in each option will vary depending on the tumour type

| Key objectives | The overall aim of the BHFT project is to develop a robust community focussed cancer aftercare pathway linking in with the existing cancer treatment pathway. The objectives of this project are to:

• support patients to navigate through the complexities of cancer care within East Berkshire given the number of organisations involved
• empower patients to maximise their quality of life through proactive self-management, signposting to existing support services and clinical support from CCM
• support patients with long term consequences of cancer treatment
• act as a resource for other community professionals and Primary Care supporting patients with cancer and other co- morbidities
• recognise possible signs of deterioration and /or recurrence linking with appropriate cancer MDT or timely referral for acute care admission |

	• utilise the project to scope the potential number of patients requiring aftercare and level of care required to inform future developments within East Berkshire
Fit with existing services	It is envisaged that the introduction of the new posts will reduce inappropriate hospital admissions by providing/helping them to access appropriate support to people in the community.
Expected outcomes/benefits	• that cancer patients at the feel supported beyond the end of their treatment • that cancer survivors know what support is available and how to access it • that cancer survivors are supported to look after their own health and wellbeing, reengage with 'normality' and get back to work • patients who experience long term side effects have someone who supports them to manage these
Project management resource input	The pilot lead has been expected to adopt this on top of her day job, and estimates that the pilot will require about 1 day per week management time.

Potential confounding factors	• The trust has undertaken significant service improvement work within palliative care/End of Life pathway, including an integrated Cancer Care Project for people living with cancer. This has resulted in good relationships being developed with GPs/acute staff which should help the integration of the new pilot roles.
	• Macmillan supports two other projects in the area:
	  - Information Centre (opened in May/June 2012
	  - Breast Cancer Project worker (due to start imminently)

Pilot site profile	
Organisation(s)	Betsi Cadwaladr University Health Board
Location	North Wales
Cancer network(s)	North Wales Cancer Network
Pilot lead(s)	Alison Foster
Posts	1WTE Macmillan Cancer Support worker 0.6WTE Macmillan Nurse – Primary Care 2 x 0.6WTE Macmillan Nurse – Community Care
Tumour sites covered	Support worker – prostate cancer Other roles – generic
Context and rationale	There are challenges associated with delivering cancer services to the rural population of North Wales, with above average levels of deprivation. Incidence and mortality rates for cancer are above average. The Health Board recognises gaps in current service provision, in particular the 'cliff edge' some patients experience when moving out of acute care. There is an evidence base in support of key workers – but clinical nurse specialists are not necessarily the answer – there is a need to look at different skill mix models. Over the last few years they have established 14 Locality groups across the region, with a strong focus on long term conditions management. One-to-one support appears to align well with this and they want to explore how it works in practice through piloting in 2 of the Localities. If successful, they hope to roll out across the other Localities.
Proposed service model	The proposed service model comprises three key elements: 1. A single pilot site for the Macmillan Support Worker project. The Support Worker will be embedded within the prostate cancer tumour service, chosen primarily for the stability of the existing MDT and the identified needs of the current service. 2. A two Locality model (North and South Denbighshire) for the Macmillan Nurses Community Care. These post holders will be involved with patients at level 2 working within existing Localities and community nursing teams identifying patients from their caseload. They will support the principles which have underpinned the development of Localities: specifically joined up working within local communities, and delivering as much as safely possible within the local community. 3. The Macmillan Nurse Primary Care will be involved with patients at level 2 working within existing GP Practices within a single Locality (South Wrexham). In particularly, this will provide an opportunity to assess the education and training needs of primary care professionals as this relates to cancer care. These 3 posts will be managed by the Locality Matrons/GP Advisor/Facilitator and supported by the Associate Chiefs of Staff (Nursing) Primary Care Specialist Medicine and Cancer CPGs. The teams will be based within the community/primary care settings and will build upon existing relationships with Cancer CPG, acute and community specialist nursing and multidisciplinary teams and social care colleagues to develop risk stratified pathways for those accessing the one-to-one service.
Key objectives	Key objectives of the support worker role are: • providing a single point of contact helping to manage patient queries • collating audit information ensuring the appropriate databases are updated

- signposting patients to the most appropriate resource
- dealing with issues on the spot to minimise patient and carer distress
- providing rapid access to intervention if and when needed
- supporting patients in the development of self-managed care plans
- providing support, advice and guidance for those with level 1 care needs
- releasing Clinical Nurse Specialist/ANP time to provide a higher level of support for patients with more complex needs

Key objectives of the primary care and community care worker roles are:

- providing a sessional commitment to support cancer patients within practices and community nurse services within their Localities
- undertaking follow-up of the low risk patient group/shared care and maintain strong links to ensure fast track back into local MDTs subject to assessment of need/identified risk
- working closely with the Specialist Palliative Care Teams within primary and secondary care and involving Macmillan Nurses Community Care roles as appropriate in seamless coordination of care and discharge
- supporting keeping care as local to the patient's home as appropriate and fast track back to acute services again as required

Fit with existing services	The post holders are already integrating well with existing services. They are working closely with Locality Matrons, with the cancer services, and with GP practices. There are two Macmillan GPs in the area who are very supportive, and are acting as advocates for the new model among medical colleagues.
Expected outcomes/benefits	Better experience and outcomes for patients: - better continuity of care - improved patient experience and outcomes post-treatment Better strategic and economic outcomes for the system: - more sustainable services - reduced unscheduled care in acute and community - enabling cancer CNSs to focus their time more appropriately
Project management resource input	The time commitment involved is currently about 1-2 sessions per week. There are other resources that can be called on, but no designated support.
Potential confounding factors	They have a patient centred work stream underway that will impact upon this project and vice versa. No other significant confounding factors are identified at this stage.

Pilot site profile	
Organisation(s)	Care Plus Group
Location	North East Lincolnshire
Cancer network(s)	Humber and Yorkshire Coast
Pilot lead(s)	Nicola Glen Lisa Revell
Posts	1 Macmillan Complex Case Manager 1 Macmillan Nurse – Community Care 1 Macmillan Nurse – Primary Care 1 Macmillan Cancer Support Worker
Tumour sites covered	No restrictions
Context and rationale	Care Plus Group is a Health and Social Care provider committed to delivering of the highest quality care closer to home. Care Plus Group is situated within North East Lincolnshire (NEL) and serves a population of 157,300. NEL is a highly deprived area, relative to other areas in the country for all of the components of deprivation, income, employment, education, crime, housing, living environment, health, etc. It has the 7th highest cancer premature mortality rate, with lung cancer accounting for the largest proportion of all cancer deaths. For all cancers (grouped together) the survival rate has improved since 1994-98 from 39.2% to 48.7% in 2000-04 in North East Lincolnshire. However, the local survival rate is still slightly lower than the average for Yorkshire and Humber (49.5%). North East Lincolnshire has seen improvements in cost effectiveness for some health programme areas in 2009/10 compared to 2008/9, particularly for cancers. However, the area still has comparatively high spend and poorer outcomes than the national average. Within NEL initiatives need to be explored that will improve the outcomes relating to cancer survivorship and also improve the outcomes for those already established as a cancer survivor. They looked at the National Patient Experience Survey data for their patients locally, and found that: • there was a lack of confidence • symptom management needed to be improved • need for clearly defined referral criteria, based on a holistic needs assessment • there needs to be a three-way discussion between the patient, the GP and the service Overall, a more holistic and personalised approach is required. They applied for all four posts in order to have: • the benefit of a whole team • peer support for the individuals • appropriate skill mix • the ability to offer a service all the time
Proposed service model	The pilot roles will be based on the existing complex case management model which is partially established for those with multiple long term conditions or those with palliative and end of life care needs. The Model works on the Five 'C's: • clinical (advanced skill and knowledge)

	• care coordination • communication • coach • care champion It is this model that the team will work within.
Key objectives	The overall aim of the pilot will be to support the patient and the family through treatment and beyond. Acting as an advocate and co-ordinating of all care, the team working together will provide a health and social care support team, which will be proactive in planning can and providing health and wellbeing advice to the patient and family/carer. This will include self-care education, sign posting, or self-symptom management.
Fit with existing services	• the complex case manager used to work in the palliative care team so that helps with integration with other services – will know which patients appropriate for each service • streamlining the pathway through better linkages between teams • better education and awareness for patients across the pathway
Expected outcomes/benefits	• they want to do a retrospective audit to see if they can demonstrate cost-efficiencies • cancer reviews – they want to demonstrate the benefits (linked to QOF payments) • individuals – has there been an improvement in their main assessed need From the patient perspective this will mean: • knowing you haven't been forgotten • better transition back into day to day life • more time with a professional rather than 5 mins with GP From the system perspective this will mean: • reduced A&E, GP visits, admissions • cost saving from seeing their team rather than GPs • increase in QoL – back to work, confidence up, social value
Project management resource input	• the pilot leads meet with the team for at least an hour per week • the palliative nurse meets with them at least an hour per week • there is a two hour working group meeting • on top of that there is ad hoc support • overall about one day per week each for each of the pilot leads
Potential confounding factors	• there is always change on the periphery, but it is not impacting directly on this pilot • they are currently bidding for additional grant funding which would enhance the service into which the 1-1 support roles are being introduced, so that could have an influence on outcomes and impact

Pilot site profile	
Organisation(s)	Ealing Hospital NHS Trust
Location	London
Cancer network(s)	NW London Cancer Network
Pilot lead(s)	Debbie Anderson
Posts	1 Macmillan Cancer Support Worker 0.6WTE Macmillan Nurse – Primary Care 0.6WTE Macmillan Nurse – Community Care 0.6WTE Macmillan Complex Case Manager
Tumour sites covered	Initial focus on Breast and Colorectal
Context and rationale	Ealing recently became an integrated care organisation under Transforming Community Services. This is expected to yield benefits in terms of shifting care into the community and the PCT has a number of long term condition priority areas where it wants this to occur. The present cancer care pathway involves specialists only. Patients with suspected cancer are referred from general practice under the 'two week rule' (must be seen within two weeks of referral) which accounts for approximately half of all those attending. Primary care practitioners contribute to care only when asked by a patient or a specialist (except for shared care for children with Great Ormond Street). Secondary care practitioners refer to tertiary and palliative care, but this also involves little shared care. Instead the different disciplines more or less 'take over' the care of patients. Ealing decided to apply for the pilot because they want to look at different ways of working, linked with the local out-of-hospital initiative. A series of models are being trialled to see if they can shift care out of a hospital setting effectively. The pilot also fits nicely with the vision of the new CCG, who are on board with the project and offering support. The rationale for going for all four roles is: • to create networks and leadership teams within the new GP network • to pilot new community based support • good fit with the horizontal and vertical integration taking place in the system Ealing believe that the role of the CCM at their pilot may be different to that of other 8as in the pilot and it will be important to explore the differences as part of the evaluation.
Proposed service model	The proposed new care pathway will involve shared care between Ealing secondary care and Ealing primary/community care. The pilot teams will provide the community-based care and will also facilitate the development of a shared care system that allows other primary/community care practitioners to contribute when appropriate. The focus will be on a) community follow up, or self-care of patients who have recovered from cancer treatment and are stratified as low risk, b) establishing a shared care process that could be adapted for patients with other long-term conditions, and c) embedding mechanisms to evaluate the cost and communication needs of shared care for cancer.

	Community follow up will include innovative ways to release the potential of patients to improve their own health and contribute to health improvement of others (e.g. Health Improvement Events). A second stage will more actively involve primary/community practitioners and will require release of funds from reduced hospital activity. It will include a) Primary care contribution to case management and shared care in partnership with the One-to-One Pilot team, b) Specialist support for primary care to increase local capacity to deal with cancer care and end of life care, c) Inter-organisational collaboration to develop shared care processes for all Long Term Conditions.
Key objectives	• provide efficient, effective and equitable patient-centred shared care in the community for patients who have cancer and cancer aftercare needs • develop innovative approaches to supported self-management • evaluate the Macmillan One-to-One Support Site in terms of numbers of patient episodes, places of care, primary care contribution to shared care, completed care plans, and patient/family/carer satisfaction with the system as a whole • evaluate the four Macmillan One-to-One Support roles – number and value of patient encounters (using Macmillan's four levels of intervention), practitioner diaries for anecdotes of quality and systemic problems, primary care satisfaction with the system as a whole, patient contribution to assessing communication problems and posting Special Patient Notes • evaluate the educational workshops and stakeholder events for their impact on learning, boundary spanning and coordinated policy • identify lessons for systems of care for Long Term Conditions other than cancer
Fit with existing services	From an outpatient perspective, they hope to see new to follow up ratios reduced, due to less routine follow up in hospital. They are not thinking about any impact on inpatients at this stage – although there may be some opportunity for reduced length of stay in colorectal (breast length of stay is already very low). Also the pilot could have an impact on avoidable emergency admissions, preventing people from showing up at A&E when they could have more appropriately received support in the community. The Trust has introduced an Enhanced Recovery Programme around 24 hr stays. There is an established programme for this at the Trust around breast cancer. The Trust is also looking at new to follow up ratios within the Trust and this pilot project could help contribute towards this.
Expected outcomes/benefits	• much more care in a community setting • better working across organisational boundaries, breaking down silos. They are hoping the new posts, particularly the complex case manager, will provide a model for working across organisational boundaries • better outcomes for patients, including improving cancer survival and earlier diagnosis of recurrence – particularly relevant in Ealing where patients tend to present later From a patient perspective, they think there may initially be some anxiety because some patients get a lot of care from the acute trust and this may be a form of 'safety blanket' for them. People can be very attached emotionally to their local hospital. However, as the new model is embedded they think patients will see the benefit of care closer to home.

Project management resource input	The project manager is new to this type of role and will need to invest time in building an in depth understanding of pathways. The project manager has 3 days a week as a project manager but she also has 3 other large portfolios (so potentially less than 1 day/week available for this pilot). There is no designated admin support in place.
Potential confounding factors	There is significant change within the system – the end of the existing PCT and the birth of the new CCG. This is leading to significant staffing and organisational change. It is unclear at this stage what the new structures will look like from March 2013 onwards, and who will be in what post.

In addition to this there is much change in the way cancer services are organised in London, under the NHS Cancer Alliance. There is a lot of pathway work going on to try to optimise the location and spread of services.

There is also a potential merger with N/W London in the pipeline. |

Pilot site profile	
Organisation(s)	Newcastle upon Tyne Hospitals NHS Foundation Trust
Location	
Cancer network(s)	North of England Cancer Network
Pilot lead(s)	
Posts	0.6 WTE Macmillan Community Care Nurse 0.6 WTE Macmillan Primary Care Nurse 0.6 WTE Macmillan Complex Case Manager 1 Macmillan Support Worker The skill mix was predetermined prior to the application process.
Tumour sites covered	All patients who are discharged from secondary care.
Context and rationale	The Trust recognise that support for patients is generally good during diagnosis and treatment stage, but that there is a gap appears in aftercare and metastatic disease. This is supported by the anecdotal information from users of our services during the DOH survey (2011) and from professionals themselves who have previously identified this gap. The Trust has therefore been exploring new and innovative ways to improve the care pathway and experience for patients with cancer and believe the 'merged' organisation (acute and community have recently merged) would be in an ideal position to pilot this innovative model, and develop a risk stratified pathway for these patients that would benefit from the One-to-One Support service.
Proposed service model	The Macmillan Nurse (Primary Care) will link with GP practices and identify patients via GP IT systems, GP registers and verbally from GP and practice nurses. The Macmillan Nurse (Community) will work very closely with their District Nursing and Social Care Colleagues and identifying patients from their caseloads. These two posts will be involved with patients at the level 2 stage developing shared care with other health care professionals. It is anticipated that both these postholders will work closely with acute colleagues, linking in with site specific nurses and ward staff to ensure patients who would benefit from the One-to One Support service are given that opportunity and follow the one-to-one pathway. The Macmillan support worker will link into all of the roles taking on the patients at level 1 encouraging and supporting self-care with open access back to the team. The Macmillan Complex Case manager will work with patients with needs at level 3, linking in to all professionals and organisations. They will also provide clinical and professional support and act as a role model to the team. It is expected that part of the role will also encompass education to other care providers including patients.
Key objectives	The aims of the One-to-One Support service are to improve patient outcomes and experience for people living with and beyond cancer so that they supported to live as healthy and active life as possible for as long as possible Objectives: • identify, assess and meet needs of patients at key points of their cancer journey • measuring patient experience and quality of care taking into account the 9 Macmillan outcomes that were identified by patients as being of paramount importance • develop risk stratification tool as per NCSI initiative (supported self-management, shared care or complex care) • develop new models of follow up e.g. best practice from long term conditions model, identification in primary/community care of patients receiving anti-cancer treatment

	- actively engage with the evaluation process - the steering group will explore sustainability and transferability of the service - develop and deliver education opportunities to other health, social and voluntary partners
Fit with existing services	The current cancer care pathway is predominately secondary care focused, however the majority of patients spend most of their time at home in community/primary care. Patients are referred via community/primary care into secondary care where they are diagnosed. Current cancer treatment is predominantly delivered within secondary care. Patients who are undergoing anticancer treatment have open access via a 24/7 hospital telephone helpline. Patients are supported at home by community services when specific care needs identified, this could involve GP, District Nurse, Practice Nurse and Social Services. Any routine follow up is undertaken in secondary care by the patient's cancer team. There is clearly a gap where currently patient's needs are not being assessed, identified or care plans developed.
Expected outcomes/benefits	They are not clear on what outcomes/benefits will be, as this is a pilot and they are keen to see what this type of support can deliver for their patients. It was also felt that it would be unfair to identify outcomes/benefits before being clear on the skillset(s) of the people they recruit into post.
Project management resource input	Jane is comparatively new in post, and cannot estimate how long she has spent on project management. She noted that it is a challenge, as service development is part of her role as a CNS, and therefore all this activity is delivered as part of her day job.
Potential confounding factors	A steering group – with representatives from social care, GPs, and secondary care has been set up so they do not envision their being any confounding factors that will influence the performance of the pilot, as they will be addressed before they can become an issue. It is worth noting that there has recently been a vertical integration of the community into the acute team, which will be monitored as the evaluation progresses. The site has also had difficulty soliciting appropriate applications for the post. The challenges can summarised as: - concern amongst prospective applicants about the sustainability of the posts/what role they would go back to after the pilot - a fundamental misunderstanding of the posts, with most applicants equating Macmillan posts with palliative/End of Life care 2 Macmillan FP facilitators have also recently been appointed.

Pilot site profile	
Organisation(s)	NHS Forth Valley Social Services within the three Community Healthcare Partnerships (NHS Forth Valley, Falkirk, Stirling and Clackmannanshire)
Location	
Cancer network(s)	NHS Forth Valley Board (West of Scotland Cancer Network)
Pilot lead(s)	Sandra Campbell
Posts	Macmillan Nurse – Community Care 1 WTE Band 6 Macmillan Support Worker 2 WTE Band 3
Tumour sites covered	The service will cover all tumour groups, and provide for all patients who complete their secondary care treatment.
Context and rationale	Although we do not have a national cancer experience survey as such in Scotland, we have a local Patient Experience Strategy in line with the national Better Together Programme (2008) with NHSFV leading in this area for many years. Local surveys in 2007 and 2008 funded by Macmillan identified the need for support for patients. An external report by Stirling University also in 2007 highlighted a gap in support. The development of the local Cancer Patient and Public Involvement (PPI) group was partly in response to these findings. The group, since 2007, have been involved in service development in various ways. This project will become a standing item on the agenda of the meetings with a plan to include them in the evaluation process. This group have given a clear message that communication and support is what is required on an ongoing basis for cancer patients. This group is also represented on the Living with Cancer Group and are active in taking forward the workplan devised as the result of a key cancer stakeholder event in 2008. The One-to-One Support pilot aims to tailor ongoing support to the needs of patients and provide a personalised holistic assessment and care planning, it will take in the needs associated with the person during and after their treatment. This project will enable and support closer working across Acute and Primary/Community Care and our Local Authority partners to deliver and improve cancer services for people and their carers. The District Nursing Service within the Community Health Partnership will play a vital role in developing a single system approach to delivering new cancer services. It will also provide and support carers to get the information they require and be aware of a pathway for the person they are caring for and allow signposting for them to appropriate services.
Proposed service model	The overall aim of becoming a pilot site would be to develop and improve the ongoing support of patients living with cancer in line with a key objective of the Scottish Government: Transforming Care After Treatment. This would include a holistic assessment at key points on the pathway. The pilot will be delivered across a cluster of GP practices within Falkirk area. This is an area where there is an excellent model of a successful joint partnership approach across health and social care and the third sector organisations to support the person in their recovery.
Key objectives	The overall aim of becoming a pilot site would be to develop and improve the ongoing support of patients living with cancer in line with a key objective of the Scottish Government: Transforming Care After Treatment.

	The objectives of becoming a pilot site would be:
	- To develop and improve the ongoing support of patients living with cancer in line with a key objective of the Scottish Government: Transforming Care After Treatment. - Introduce a holistic needs assessment at key points along the pathway and ensuring every patient with a cancer diagnosis has a point of contact for support. - The development of a risk stratified pathway for those patients who access the One-to-One Support service. - Develop a new pathway to involve the patients meeting the named community support either HCSW or DN in the immediate post treatment period (which is identified as one of the most difficult times for cancer patients) and would be known to the patient as the point of contact from thereon, whilst the existing cancer pathway facilitates support from the CNS from diagnosis to death for most patients, there are inconsistencies and inequity between the different cancers as to how that is provided. (See Appendix2) - The community DN/HCSW would have direct access to the CNS and therefore back into the acute care service if required. The new pathway will enable NHSFV to deliver on the vision of the oncology/palliative care nursing team which focuses on equity of care. See appendix 3 - Implement the roles across a number of GP practices - Implement a triage/support line as a single point of contact for patients and carers - This model is proposed to maximise benefit of funding and cascade supportive ethos throughout the DN community. Through planned awareness sessions this will aim to optimise sustainability as will become normal day to day practice. They will develop a Single Point of Contact for all 3 CHPs developing pathways across health and social care. - This service will deliver across community, primary care, acute and social services along with other non-statutory organisations such as hospice and care homes, the postholders will have the confidence and competence to deliver across all organisational and professional levels to ensure the care for people is of quality. - Development of balanced score card specific to the role that will allow ongoing collection of data to inform annual reports - Pilot End of Treatment Summary
Fit with existing services	There is currently no consistent support in the community for patients who are discharged from secondary care. This pilot aims to provide support to all cancer patients when they complete their treatment and are discharged from secondary care.
Expected outcomes/benefits	The key expected outcomes and benefits are: - To help people living with cancer (and their families) to get normality back into their lives - Support people living with cancer to manage their condition - Support people with cancer to better understand the signs of recurrence, and easily renter the system to get the support they require - Improve communication across the healthcare system to create a seamless pathway for cancer patients
Project management resource input	Unable to estimate.

Potential confounding factors	The Strategic Cancer Board directs the developments and strategic implementation of cancer and palliative care services. Work has been progressing in partnership with Macmillan Cancer Support and NHS Forth Valley to redesign the Oncology/Palliative Care Nursing Services. This has led to progress work in the following areas: • A 3-5 workforce plan is being developed to shape up the future provision of Oncology/Palliative Care Nursing. • Economic modelling of the cost of cancer care. • Dr Paul Baughan is leading on End of Treatment Summary which will be supported through the project • Evaluation of a Post Cancer Treatment group, based on the principles of the survivorship agenda is in progress. • District Nurse support for patients in implementation of 4 new pathways for less common cancers: brain tumours, sarcoma, melanoma and unknown primary. • CNS support in care homes and prisons. • Patient experience projects • Introduction of Health Needs Assessment for all patients with a cancer diagnosis and a consistent approach to psychological assessment. • The Macmillan adopted oncology team is now well embedded within NHSFV and has allowed a shift towards a more generic sharing of support provided to the patient within the team. The development of Health Care Support Worker role in chemotherapy and stoma care has brought about improved changes to the patients journey. There is increasingly more collaboration with local authority as it is recognised that sharing of care across health and social care maximises resources, improves the patient experience and outcomes for the patient and carer.

Pilot site profile	
Organisation(s)	NHS Oldham (Sponsor) Pennine Care NHS Foundation Trust (Host)
Location	Oldham
Cancer network(s)	Greater Manchester and Cheshire
Pilot lead(s)	Richard Roberts
Posts	0.6WTE Macmillan Complex Case Manager 0.6WTE Macmillan Nurse – Primary Care 1WTE Macmillan Cancer Support Worker
Tumour sites covered	No restriction
Context and rationale	There are limited and variable cancer follow-up and aftercare services in Primary Care and community health services. The traditional role of Primary Care has been limited to prevention, screening, early diagnosis and end-of-life care whilst provision of systematic cancer care review, survivorship models, long-term condition management and aftercare are at best patchy. The project will pilot a systematic primary and community care support pathway for patients diagnosed with cancer as well as those at risk or in fear of developing cancer. It will endeavour to create a new sustainable primary care model of providing holistic patient and family support, from time of cancer diagnosis, throughout treatment and into aftercare, complemented by an element of lifestyle coaching to reduce the likelihood of cancer and recurrence of cancer, as well as promotion of screening and early diagnosis. The systematic long-term condition management approach for cancer patients is anticipated to provide improved care and support for people with cancer whilst making best and most appropriate use of existing specialist health, social care & carer support services. It is hoped to prove cost effective through reduction of urgent care activity and thereby become a sustainable best practice model for the future. The rationale for going for three of the four roles was that they think it will be beneficial to have the whole package, and will be much more effective with the roles working together and supporting each other. They didn't think the fourth role was so relevant in their context.
Proposed service model	Primary care – it is about making sure that patients are on registers to start with, and then providing patients with support on that pathway within 6-12 months of treatment. Particularly creating a legacy of cooperation with practices that can be sustained. Complex case mgr – they will have a caseload of approx. 20 patients with very specific needs, based on a risk stratification. They think the roles will be generic, working across all cancer sites. They are going to be working with two cluster groups of GP practices – 12 GP practices in total, rather than the full 50 practices in the area.
Key objectives	• holistic, seamless support • cost effective and better quality care • avoid patients feeling isolated • personalised care plans and information prescriptions • proactive management of patients with complex needs • single point of access for patients, carers and professionals

Fit with existing services	This service will complement and integrate with existing services for cancer patients in community and secondary care.
Expected outcomes/benefits	- primary care - increased cancer care reviews undertaken in general practice and to a higher standard - complex case manager – appropriate cohort of patients being seen, leading to improved clinical outcomes and reduced unnecessary hospital admissions - support worker – better engagement, better signposting, more referrals into the appropriate setting - good quality evidence to roll out the project across NHS Oldham – positive outcomes, and opportunity to embed - create a legacy – getting ownership from GP practices
Project management resource input	About 4-5 hours a week at the moment.
Potential confounding factors	It will be important for their pilot to be linked in with the Manchester Macmillan pilot. Also they have an Oldham cancer support centre so it's important they don't work in isolation. Christies are going to be introducing a survivorship programme. The change to the CCG will not have too great an impact because there will be continuity of personnel.

Pilot site profile	
Organisation(s)	Queen Victoria Hospital NHS Foundation Trust (QVH)
Location	Sussex
Cancer network(s)	Kent & Medway, SWSH and Sussex
Pilot lead(s)	Amanda Parker Pauline Mortimer
Posts	1 Macmillan Complex Case Manager 1 Macmillan Cancer Support Worker
Tumour sites covered	Breast, skin, head and neck
Context and rationale	QVH works as a tertiary centre, across three cancer networks, and provides the surgical aspect of patients' treatment plans for major head and neck, malignant melanomas, skin and breast cancers often involving complex reconstructive surgery. Often patients who undergo surgery at QVH have complex discharge arrangements. Currently this involves a multitude of agencies which are not always aligned, especially when the patient has come across county boundaries. The ability to ensure that complex cancers across the region are managed in a timely manner can be challenging and the current expectation for one Macmillan nurse, for each of the speciality areas, to manage these patients, while also attending network and MDT meetings can at times be unrealistic. QVH feels there is an opportunity to improve coordination with local and specialist MDTs and other agencies to support the management of patient care from diagnosis through to completion of treatment, ensuring patients do not 'fall off the radar' at any point in this pathway.
Proposed service model	The aim of the pilot is to provide an integrated model of cancer support, from a tertiary centre, that provides regional holistic expert care, for complex cancers covering the time the patient is referred through to discharge. The appointment of both the CCM and SW will provide cancer patients with a holistic model of care. The two roles will be incorporated into the wider team operating out of a central hub based at QVH. This will enable the current cover provided by QVH to be extended both from referral and beyond discharge. **CCM** - will provide an opportunity to observe how support can be delivered to patients and their relatives, through developing links with multiple healthcare and social care professionals involved across a wide regional area. The CCM will also provide a focus point for a more holistic and seamless passage of care through all stages of care, linking with primary care and reducing hurdles to improve the overall experience. They will also be responsible for providing regional education and delivering service redesign, as well as ensuring that commissioners of cancer pathways are involved to streamline processes across organisations particularly for complex cases in Sussex and Kent. **SW** - will complement and strengthen the existing team comprising of CNSs and the Information Centre Manager. The support role will be able to work alongside the centre to provide a single access point for patients and their carers for information, education and support by fielding general calls. This in turn in intended to free up time for the CNSs and the CCM to deal with more complex patient needs.

Key objectives	• all patients having access to a central Macmillan cancer nurse for support with improved links between organisations • all patients seen at QVH having a single point of access and patients experience is not hampered by region • reduced inappropriate admissions of cancer patients by allowing patients to re-access services without delay • increased number of patients feeling a sense of leading a normal life as possible with cancer • provision of expertise and training for relatives, carers and professionals • identification of gaps in services particularly in community to commissioners via the cancer networks • release CNS time to focus on where their specialist skills are most needed • increase skill mix in cancer team
Fit with existing services	This pilot does not aim to change the patient pathways but to enhance them. The roles will be integrated within existing teams, and work alongside the current Macmillan nurses.
Expected outcomes/benefits	• aid the transition of patients and those around them from the time they are booked for surgery through to discharge into the community • extend the expertise from a tertiary centre to the community by working with and training staff • enhance the care the patient receives in order to reduce unnecessary admissions to hospital and improve life beyond cancer • complement the newly opened Information Centre by providing a single access point for patients and their carers for information, education and support by fielding general calls • patients receive right information, a quicker response and a more holistic approach to their care • release CNS time onsite and allowing the CCM to deal with more complex patient needs as referred by the SW • facilitate liaison with secondary providers and patients to co-ordinate dates for surgery involving visiting consultants
Project management resource input	Time input required to manage the pilot is not too onerous at the moment, since the roles are integrated within existing teams. When the new 8a manager is in post the site will have clearer idea of time input required from them. No designated admin support for the project is available, but the SW post has an admin side to it, and there is access to an existing PA.
Potential confounding factors	• the pilot is looking to co-locate people who are currently working out of many different offices – to improve communications. This may contribute to more seamless working. • there are also some changes to the line management structure about to happen with one of the band 7s stepping up to an 8a as a manager. • there are some phase 2 projects coming on stream e.g. West Sussex PCT will have a complex care manager of their own in post.

Pilot site profile	
Organisation(s)	South Eastern Health and Social Care Trust
Location	Northern Ireland
Cancer network(s)	Northern Ireland Cancer Network
Pilot lead(s)	Caroline Lynas Heather Finlay
Posts	2 x 0.5 WTE Macmillan Nurse – Community Care 2 x Macmillan Support Worker
Tumour sites covered	These roles will be piloted specifically within the Breast, Colorectal and Urology services.
Context and rationale	The underpinning principles of Cancer Services outlined within the Strategic Cancer Plan 2008-2013 are to provide services that are: - patient focused - developed collaboratively in partnership with statutory and voluntary bodies including services users - integrated and seamless to provide flexible and responsive services - delivered within the context of the Health and Social Services strategic goals Building on the strategic plan the Trust is currently working towards, implementation of the objectives in "Transforming your Care" and the requirements of the Quality Improvement and Cost Reduction Programme, recently published reports following a comprehensive review of the Health Service in N Ireland. These reports recommend transformational change to improve services addressing: - improved management of long term conditions - the need to move to community based treatment and care with hospital outreach - increased productivity and efficiency throughout all Trust services - improved patient flow The overall aim is to provide person-centred care tailored to individual needs, supported through a case management approach that will improve the quality of care and support available to users and their carers and obviate frequent, but fundamentally avoidable, admissions to hospital.
Proposed service model	The roles would be piloted specifically within the Breast, Colorectal and Urology Services for the following reasons: - already committed to the principles of TCFU and service reform - moving to a process of risk stratification with self-management where appropriate and holistic assessment at key points in the patient journey - working with specific tumour sites gives the opportunity for service redesign to meet the challenge of "Transforming your Care" and to identify and evaluate the effectiveness of each role according to tumour site with comparison of outputs - well established MDTs with strong nursing and medical leadership Both roles would be closely aligned into both the acute sector MDT and primary care teams including GPs and District Nurses supporting integrated care and a smooth transition of care from secondary to primary care with enhanced communication across all boundaries. It is anticipated that the initial focus for the support worker role would be secondary care working alongside the relevant MDT with a gradual shift to primary care.

Key objectives	The key objectives of the Macmillan Support Worker will be to: • signpost patients to the most appropriate resource • support patients in development of self-managed care plans • release CNS time to provide a higher level of support to patients with increased complexity • triage phone calls providing basic telephone advice • co-ordinate assessments, appointments and investigations • support the co-ordination of Health and Well Being Clinics • co-ordinate education and support for people with non-complex care needs • co-ordinate handover to other teams • provide education and access to appropriate resources for patients and their relatives The key objectives for the Macmillan Nurse Community Care will be to: • provide proactive aftercare for people living with cancer • receive all Treatment Record Summaries (TRS) and provide ongoing holistic assessment • proactively manage the cancer care review of patients who have completed treatment • proactively manage ongoing surveillance where appropriate such as PSA testing in urology to reduce the need for hospital review • facilitate and enable the education of primary health care teams
Fit with existing services	Although the current pathway has some variation across all three tumour sites, the broad principles are consistent: • patients receive intensive support from diagnosis and through treatment; however, gaps are noted following discharge and this has been reported locally through patient satisfaction surveys and the user forum. Focus has been on the clinical aspects of management with limited attention to cultural and attitudinal change from illness to a focus on recovery, health and well-being • holistic assessment is currently available at pre-assessment prior to surgery and not on completion of treatment • tailored after-care pathways based on risk of future problems are currently unavailable • limited opportunity to introduce rehabilitative measures to reduce co-morbidities • duplication in follow-up practice with inefficiencies exacerbated by the fact that many appointments add little value for patient or doctor • there are indications that patients' needs are not adequately addressed nor are they getting the help they need to get their lives back on track The main changes to the current pathways will be on discharge following initial treatment and also in relation to ongoing follow-up with: • enhanced individualised support following discharge with focus on social, cultural and rehabilitative needs • holistic assessment provided at agreed points following completion of treatment and rapid access back to the MDT • signposting to other services on receipt of TRS to minimise risk of future problems associated with both cancer type and co-morbidities • reduction in hospital appointments with surveillance provided closer to home • reduced reliance on hospital teams • releasing time for the CNSs to focus on complex care • care co-ordination across care setting ensuring consistency of service delivery through appropriate service commissioning

Expected outcomes/benefits	The recent review of Health and Social Care in Northern Ireland (the Compton Review – Transforming Your Care) made 99 recommendations on improving care for patients and effectively meet demand with finite resources. A number of these recommendations relate to transferring care in the community, and have been picked up in the trust's Strategic Cancer Plan, which places an emphasis on providing services that are patient focused and integrated. This pilot will be given ownership of managing cancer (following acute treatment) in the community, and it is therefore hoped that they will effectively deliver patient focused services in the community in a cost effective fashion.
Project management resource input	The management of the pilot is being absorbed into their existing workload – best estimate is 4-5 hours per week of additional time.
Potential confounding factors	The main confounding factor they anticipate having an impact on the performance of the roles is resistance from the existing community and district nursing teams. For the roles to deliver the anticipated outcomes and impacts, the new post holders will need to work closely with the existing nursing teams who deliver the existing care for people living with cancer as part of their wider remit. A key challenge for the team will be to ensure that existing nursing teams see the new posts as providing additional support and expertise to patients, rather than duplicating their work or posing a threat to them.

Pilot site profile	
Organisation(s)	The Royal Marsden NHS Foundation Trust
Location	London
Cancer network(s)	SW London
Pilot lead(s)	Theresa Wiseman
Posts	2 Macmillan Cancer Support worker (1 breast and 1 GI) 0.6WTE Macmillan Nurse – Primary Care 0.6WTE Macmillan Nurse – Community Care 0.6EWTE Macmillan Complex Case Manager
Tumour sites covered	Breast and Gastro-intestinal
Context and rationale	They decided to apply to be a pilot site because: • the pilot lead is part of the Macmillan Community of Influence group – they want to tweak the pathways to make them more seamless • the acute trust joined with community services in March 2011 – and this is an opportunity to work across acute and community to deliver seamless care The rationale for going for all 4 posts is to see how the whole system would work, rather than just one element of it.
Proposed service model	The aim of the project is to test the effectiveness of the 4 new roles in supporting a sustainable aftercare model which integrates primary and tertiary care and provides the most effective and accessible care for people affected by cancer. The support workers will work within multi-disciplinary teams in the hospital and the community posts will cover a cluster of GP practices. In 2 years' time, they would like to see: • SWs embedded within the multi-disciplinary team • in team meetings SWs get list of next patients to see • SWs link with the patients • proper end of treatment assessment and learning for all patients • SW hands over to practice nurse, indicating what level of risk and what kind and level of support people need • community nurses follow up • whenever a need is flagged up they are signposted to the relevant service
Key objectives	• implementation of a new aftercare model for people with cancer which crosses both acute and primary care settings • to improve patient-reported outcomes and patient experience • to have greater GP/community involvement with people living with and beyond cancer • development of primary/tertiary care liaison model • linking patient pathways to HNA and care planning (according to patient risk stratification) in acute and primary care • improved communications (and documentation) between GPs/community care, acute oncology services, social care and the patient and family • reduced unplanned hospital admissions and length of stay for people living with and beyond cancer treatment

	• to evaluate the feasibility, processes and impact of the new roles as well as the new aftercare pathway • to work with the Macmillan evaluation team to deliver a robust evaluation with national comparisons
Fit with existing services	It will impact on the pathway. The pilot intends for patients to access much more support in a community rather than a hospital setting. They also hope patients will start to see the end of their treatment as a transition into a different kind of support rather than a stop dead. When patients want or need to get back into the system, they will be able to more easily. But at the same time patients who are needlessly coming back into the system for routine follow up will be supported in a different way. Their confidence in community services will be built. Therefore there will be benefits for both the patient and the system.
Expected outcomes/benefits	Seamless, integrated, holistic care. For patients this will mean: • a route back into their usual way of being • a single point of contact for questions • more integrated and holistic approach
Project management resource input	There is a quite a big time commitment. It is not protected. For about 3 months the pilot lead was spending approx. 1 – 2 days a week on this. Now it has settled down to approx. 2-3 hours / week. After about 6-9 months she expects this to reduce to perhaps 0.5 days per month, once the roles are embedded. In addition to this there is the time of the direct line managers, which she estimates to be at least 0.5 days per week. Admin support is available via an existing PA.
Potential confounding factors	Commissioning – when the pilot adjusts the pathway to nurse led, they are not currently paid for this by commissioners.

Pilot site profile	
Organisation(s)	University Hospitals Bristol NHS Foundation Trust North Bristol NHS Trust South Gloucestershire Community Health Services Bristol Community Health Community Interest Company
Location	Bristol
Cancer network(s)	Avon, Somerset and Wiltshire Cancer Services Network
Pilot lead(s)	Ruth Hendy Claire Chapman Elizabeth Potter Sue Parris
Posts	1.2 WTE Macmillan Community Care Nurse 1.2 WTE Macmillan Complex Case Manager 2 Macmillan Support Workers
Tumour sites covered	Initially Lung and Upper GI
Context and rationale	This is an opportunity for collaborative working across the Bristol health community. University Hospitals Bristol NHS Foundation Trust (UHBristol), North Bristol NHS Trust (NBT), South Gloucestershire Community Health Services (SGCHS, hosted by NBT) and Bristol Community Health Community Interest Company (BCH CIC) will act as a pan-Bristol pilot site, and provide an integrated approach to one-to-one support of their shared cancer population.
Proposed service model	Cancer patients will have a Holistic Needs Assessment carried out whilst they are under the care of the Acute Trusts (UHBristol and NBT), usually this will be done by a Clinical Nurse Specialist following surgery or during chemotherapy/radiotherapy. Patients will then be risk stratified into red, amber or green and their ongoing care needs will be structured in relation to this. The Cancer Support Worker will: • provide a single point of access for patients • organise post treatment self-management programmes (as guided by clinical staff) • coordinate care for patients with non-complex needs (those stratified 'green') • enable navigation of the health and social care system for cancer patients • coordinate ongoing care /support through direct links to the community nurse/complex case manager posts Patients with shared care needs (amber) will be referred to the Community Nurse posts for additional support. Those patients identified as having complex care needs (red) will be referred to the Complex Case Manager posts.
Key objectives	These services provided by the pilot posts will: • support people in regaining as normal a life as possible after treatment • minimise the risk of developing further cancer-related problems • give information, advice and support about long term effects of treatment and how to minimise the effects • provide appropriate advice and support in the early identification of advancing disease, and how to manage this effectively • enable people to re-access cancer and specialist services without delay should they need

Fit with existing services	The service will link closely with clinicians in the Acute Trusts to ensure that patients receive the holistic needs assessment. The current pathway is: • patients (form BCH CIC or SGCHS GPs) referred to secondary care at NBT or UHBristol within target timescales • surgery at NBT / UHBristol (depending on centralised specialities) • if required, referred on to Bristol Haematology and Oncology Centre (UHBristol) • oncologists / surgeons / Clinical Nurse Specialists (CNS) already involved in cross NBT / UHBristol working • Acute Trust CNS contact with patient at diagnosis – continue support through pathway • patient in and out of acute care throughout oncology treatment • multi-professional liaison required across community / Primary / secondary care throughout this time, no clear designated process for shared care • care in the community focused on the immediate physical needs at the point of discharge from secondary care • discharge summary (from acute care) summarises the treatment provided/ongoing, current medication and may include other health care needs (e.g. wound management or IV line management) • no coordinated approach between community / practices and hospitals If a GP/community/primary care require further information, advice or support for a cancer patient in their care, they use a number of routes to access this: • a Consultant's secretary • named hospital clinical nurse specialist • inpatient ward at BHOC (if a patient had recently been discharged) • urgent outpatient appointment at the appropriate hospital • refer to GP Support Unit at either Trust • present at ED at either Trust Ultimately, it is often the clinical nurse specialist who tries to co-ordinate the pathway and manages problems from within secondary care. After treatment, cancer patients continue to move between Acute Trusts and their Primary/community care settings, receiving varying levels of care and support depending on the cancer expertise and communication links within their locality.
Expected outcomes/benefits	• improved patient experience for cancer patients across Bristol/South Gloucestershire • establishment of a sustainable model of aftercare that meets patients expectations and requirements • provide learning that can be shared with other pathways
Project management resource input	Fluctuates between four and ten hours per week, depending on the demands of the project at any given point. Estimates that the average is around five hours per week.
Potential confounding factors	There are a number of other service improvement projects that could impact this pilot: • have submitted a bid to Macmillan to create a vocational rehabilitation service. If successful, the post will commence in April 2013 • North Bristol Survivorship Programme: recently submitted a mini-business case to sustain and develop the survivorship, exercise and diet service. This service is also trialling a holistic needs assessment process • North Bristol NHS Trust has been a pilot site for the recent National Cancer Survivorship Initiative

Pilot site profile	
Organisation(s)	University Hospital Southampton NHS Foundation Trust Southampton City PCT
Location	Southampton
Cancer network(s)	Central South Coast Cancer Network
Pilot lead(s)	Alison Keen (Evaluation Lead)
Posts	1 Macmillan Complex Case Manager 2 Macmillan Support Workers The site tendered for these posts because they had an identified need (described below) and this resource enabled them to fill this gap.
Tumour sites covered	Testicular, Colorectal, Breast
Context and rationale	This project is being led by the University Hospital Southampton NHS Trust. The overall aim of the pilot is to build upon the NCSI cancer after care project which has been in place since November 2009. One Macmillan CCM and two Macmillan Support workers will be employed as part of this pilot project. NHS Southampton supports the needs of around 250,000 people living within a relatively small geographic urban area, with significant health inequalities and health generally worse than the England average.
Proposed service model	The new pathway for the pilot of the CCM role will be for patients with advanced and progressive disease (breast and gynaecological cancers) and for patients who have completed curative treatment and are on self-managed follow up pathways. The two new roles are intended to enable the new pathways as follows: • care coordination – streamline and coordinate survivor aftercare (complementary function within the current MDT) of clinical and non-clinical services and to ensure the patient is seen by the appropriate person, and in a timely manner • contribute to the care of patients on supported self-managed pathways • coordination of self -management interventions: plan, organise, coordinate, evaluate, and support delivery of the annual programme of self -management support interventions for all patients in level 1 pathways Complex case management is going to enable new pathways for women with secondary disease to experience coordinated, supportive care for their varying intensity of needs. It will be community based and straddle and integrate specialist MDTs with targeted proactive primary and social care services. This will involve anticipatory care planning which will lead to improved quality and patient experience.
Key objectives	Specific objectives for the pilot include: • expanding the use of risk stratification which informs level of care, patient pathways and effective aftercare models • design and pilot the Macmillan Cancer Support Worker post into one which will enhance patient experience at the level one supported self-management pathways for breast, colorectal, testicular, and endometrial cancers • redesign care pathways for patients with advanced and progressive disease (breast and gynaecological – levels two and three care) and to pilot the Macmillan Complex Case Manager role

Fit with existing services	The new service will work very closely with existing provision, building on the work undertaken to date.
Expected outcomes/benefits	The expected outcomes and benefits are: • that the pilot will provide a clear template for the future, and a roadmap for providing patients with the right support at the right time • provide patients with a better quality of care through self-managed pathways in the community • a streamlined and coordinated approach to survivor aftercare that ensures that patients are seen by the appropriate person in a timely manner
Project management resource input	Has one day per week allocated to this role.

Pilot site profile	
Organisation(s)	Western Health and Social Care Trust
Location	Londonderry
Cancer network(s)	Northern Ireland
Pilot lead(s)	Coleen Harkin Bernie Michaelides Elizabeth England
Posts	0.5WTE Macmillan Complex Case Manager 0.5WTE Macmillan Nurse – Community Care 1WTE Macmillan Cancer Support Worker
Tumour sites covered	Breast and Urology
Context and rationale	The Trust has embraced long term conditions management through the case management model in place since 2008. Case managers work in close partnership with both primary and secondary health care professionals for these specific disease processes. It is very evident that whilst this model is very successful, the needs of the patients living with cancer are not being met. Some patients are held in an acute setting for too long – this disables them rather than empowering them to take responsibility for their own health. They want to both give patients the knowledge, and change the staff culture to enable this to happen. Following discharge from acute services, these patients require ongoing support and signposting to relevant voluntary and statutory services in a timely manner to prevent unnecessary re-entry into acute services. It will be challenging and need to be handled very well, so patients don't think they are being abandoned. In West Northern Ireland there are very high levels of deprivation and poor health outcomes, so they will need appropriate screening to ensure patients are able to self-manage. They will be working v closely with community groups – tapping into the strong community networks that exist. The rationale for going for the three roles is that together they will provide seamlessness across acute-community-self management.
Proposed service model	It is proposed for the purposes of the funding that the pilot will focus on the northern sector (i.e. Londonderry and Limavady) of the Western Trust area with the main acute hospital being Altnagelvin. The pilot will integrate into the already established NICaN cancer pathways for breast and prostate as attached. It is envisaged the pathways will be enhanced with particular reference to Transforming Cancer Follow-up and the pathways associated with the risk stratified model of care. The Macmillan One-to-One Support team will identify patients with the site specific teams for breast and urology at the most appropriate point to commence the self-management model. Whilst the current pathways attached involve diagnostic screening, assessment and treatment, it is envisaged the One-to-One Support team intervention will be at the point of completion of treatment. This will enable patients to embrace self-management which is currently not part of the cancer pathway. The Trust is committed to linking into the ongoing regional work for the development of pathways for cancer of unknown primary.

Key objectives	The overall aim of the pilot is to ensure that patients living with cancer are supported and educated in self-management to live with or beyond cancer, and integrate back into their community. In doing so the team will ensure "individuals will have the opportunity to make decisions that help maintain good health and wellbeing" (Transforming Your Care: A Review of Health & Social Care NI, January 2012). The objectives are: • a seamless transition for patients in their cancer journey • supporting and signposting patients to relevant voluntary and statutory services in a timely manner • improving coordination of community care and achieving a more holistic approach for patients • to improve patient/ carers experience and outcomes • support patient choice (i.e. preferred place of care) • reduction in re-referrals/ hospital consultant appointments • to support patients in the self-management process and reduce reliance on core services.
Fit with existing services	They already have a LTCs team well established and the CCM will integrate within this. The other posts will sit with the cancer services team. They are just setting up the steering group – and they are going to run it back to back with the TCFU steering group, with same personnel, to ensure alignment.
Expected outcomes/benefits	• seamless transition • self-care model • using voluntary and statutory services appropriately • improving coordination between acute and community • holistic treatment and care • improved patient experience • gain patient trust • could be a reduction in re-referrals
Project management resource input	Considerable amount of time spent on the application process, talking it through, clarifying the vision – has been time well spent In future the posts will become part of the service and will be managed as such They are not using language around 'pilot' because selling it as a service change that will be embedded, not a bolt on. Nevertheless they do have the project infrastructure in place.
Potential confounding factors	There is lots of change going on, in particular the shift of care from acute to community.

Logic Model

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Theory of change logic model: Phase 1 of the One-to-One Support implementation project

Context/rationale	Inputs/activities	Outcomes		Long term impact

Context/rationale

The cancer story is changing

Survival rates for cancer are improving, so there is a growing number of people who have are living but they are not necessarily living well

These people have ongoing unmet needs from their cancer and treatment e.g. late side effects of treatment, greater risk of other LTCs, risk/fear of cancer recurrence

People with incurable cancer are also living with their cancer for longer, and have ongoing needs associated with their cancer and co-morbidities

The health and social care system needs to change in line with the changing cancer story

The current system is not meeting the needs of people living with and beyond cancer

Building cancer care teams for the future means having the right person, with the right skills, in the right place to deliver care that meets the needs of people living with and beyond cancer

The gap for one-to-one support is estimated at 3401 posts across the UK, but it is unlikely all of these posts need to be Band 7 CNSs

Other generalist roles and lower grade roles can provide support and care to less complex cases, freeing up CNSs to provide specialist support to the smaller proportion of those with complex needs, based on a risk stratification approach

It has been estimated that up to 33% of the gap in CNSs could be filled by a Level 4 post (NHS Career Framework, 2009)

Generalist posts, already working with other LTCs, can be up-skilled to support people with cancer – a risk stratification approach to care is already in place for other LTCs

There is a drive to deliver care in the community and closer to home, to improve patient experience and meet needs after treatment

Macmillan wants to be at the forefront of this change

Macmillan has publicly committed to investing up to £300m over the next 7-10 years to fill the gap across the UK

Macmillan wants to work with partners to pilot a menu of solutions, in order to understand what works well and not so well in order to implement one-to-one support

One-to-one Support is a core part of Macmillan's Workforce Strategy which has been identified as one of the key transformational change areas

Inputs/activities

Introduction of new posts into health and social care across the UK, to complement existing posts

26 x Macmillan Cancer Support Workers – Care Coordination (cancer specific, providing Level 1 self-care with support and open access to MDT)

26 x Macmillan Nurses Primary Care or Macmillan Nurses Community Care (generalist LTC roles, released on a sessional basis to review support to people with cancer, providing Level 2 Shared Care)

13 x Macmillan Complex Case Managers (could be specialist or generalist – e.g. Modern Matron – providing Level 3 Complex Management through MDT)

Max funding of 2 years for each post

Pilot sites may have more than one of these roles – numbers and mix of roles will depend on need/context

Delivery will be phased – approx 50% in Wave 1 and 50% in Wave 2

Working with existing teams to act as a catalyst for change to provide One-to-One support

One-to-One support is understood as a service delivered by a team comprising of specialists (e.g. CNSs and AHPs – Levels 6 and 7) and generalists (e.g. Level 4 Support Worker, District and Practice Nurses) who support the patient across the whole cancer pathway, based on the intensity and nature of the needs of patients and tailored to meet those needs by following the principles of good care

Central support and leadership from Macmillan

External evaluation to capture evidence and learning

Learn and share events to bring pilots together and support peer learning

Access to Macmillan Learning and Development opportunities for Macmillan Professionals

Comms and marketing of the project

Working Group to oversee implementation

Outcomes

Successful implementation of posts

High quality applicants apply for the posts and are recruited

There is a good spread of the new posts across the UK, in a range of settings and within different teams

The roles are accepted by peers and seen as credible and as complementary to existing roles

Increased awareness, knowledge and skills among postholders

Postholders have increased awareness and knowledge around cancer, its treatment and the changing cancer story

Awareness and knowledge is transferred to other health and social care professionals within their teams

Postholders develop new skills needed to carry out their roles

Postholders feel well equipped to identify needs of people affected by cancer and necessary changes to health and social care

Changes to the care pathway

Other health and social care professionals accept the need for change and feel involved in the process

Key partners understand what needs to change and why

Changes are made to the whole cancer care pathway to better meet the needs of people living with and beyond cancer

Services are more joined up and better coordinated

Improved quality of care and patient experience

People with cancer feel that:

their individual needs are thoroughly assessed and understood

they are involved in planning the treatment and support needed to meet their needs

the different aspects of their treatment and care are well co-ordinated and there is good communication between different professionals supporting them

the professionals supporting them communicate well with them and treat them as an individual, and with dignity and respect

they have trust and confidence in the professionals caring for them

they are receiving good care and support following the end of their treatment (including care in relation to consequences of my cancer and/or its treatment)

they receive good, timely and accessible info, and are supported to understand it

they are supported to make decisions about their treatment and care, and to manage the physical, emotional and practical impact of cancer

people around them understand what living with cancer is like

their family and friends receive emotional, financial and practical support and info

Improved clinical outcomes

People with cancer have an improved quality of life, included reduced stress and anxiety

People affected by cancer recognise signs of recurrence, know where to go for help and present early

Improved productivity

Specialist roles (e.g. CNSs) are freed up to deal with complex cases

Number of people supported to control their own health/self-manage is increased

Reduced unscheduled hospital admissions

Reduced length of stay in hospital

Reduced use of other health and social care services

Knowing what works

Macmillan and our partners will know whether these roles work in practice, where the gaps are and what further changes need to be made

Long term impact

Cancer recurrence will be diagnosed earlier

Improved survival rates and people living longer with secondary cancer

More people affected by cancer will have been supported by a Macmillan professional

People affected by cancer will have a greater awareness of Macmillan, our role in changing cancer care, and how we support people affected by cancer

People affected by cancer will feel part of a community and be inspired to give something back/support Macmillan

Macmillan will be seen to be working with health and social care professionals and policy-makers in leading and demonstrating best practice in the new cancer story and will have a greater influence across the UK

Other health and social care professionals and policy-makers across the UK will understand the changing cancer story, see the need to change cancer care, and understand the value of these roles

Macmillan is seen as the thought leader on issues relating to the cancer workforce