WE ARE MACMILLAN.
CANCER SUPPORT

EVALUATION
OF PHASE 1 OF THE
ONE-TO-ONE
SUPPORT
IMPLEMENTATION PROJECT

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Contents

1 Introduction

Macmillan Cancer Support carried out a major project to pilot new ways of providing one-to-one support for people with cancer across the UK. The process is split across two phases, with phase 1 (April 2012–November 2014) piloting the new approach in 16 sites across England, Wales, Scotland and Northern Ireland.

Macmillan has committed to investing £300 million over the next 7–10 years to support the NHS – a substantial investment of resources – which represents a significant opportunity to:

- improve the quality of care, quality of life and experience for people living with a diagnosis of cancer, their 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, and a number of the sites included in phase 1 has a further years funding to carry out further testing of the roles.[1] Macmillan is strongly committed to developing this approach and type of

support in the longterm, and the findings and learning from the evaluation of phase 1 will be used to shape subsequent investment in support for people affected by cancer.

One-to-one support for people living with a diagnosis of cancer might best be understood as a service that supports their journey across the whole cancer pathway, based on the intensity and nature of their needs, to improve quality of care and patient experience and outcomes in a more cost effective way. Phase 1 of the project involved 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.

1. At the time of writing four sites had been successful in their application for extension funding.

Macmillan commissioned a consortium led by Frontline, in partnership with the University of West of England at Bristol and BresMed Health Solutions to evaluate Phase 1 of the pilot. This report builds on the early research presented in the baseline[2] and interim reports to update the progress at each pilot site and provide the analysis of:

• policy context and strategic fit with one-to-one support approach
• the impact of one-to-one support on people affected by cancer
• how the services have evolved and developed – how they work and who they work with
• an economic analysis of the impact of one-to-one support posts
• key learning points for Macmillan and the future delivery of support for cancer survivors

1.1 Cancer in the UK and the drivers of one-to-one support

The cancer story in the UK is changing. The latest figures indicate that there will be two and a half million people living with or beyond cancer in the UK in 2015, 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[3]. 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 £5.13 billion in direct costs to the NHS, with a further

£0.36 billion for hospice care[4]), 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 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 support.

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

2. Available at: http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/OnetoOnesupport/Onetoonesupportbaselinereport.pdf
3. *Facts and Figures,* Macmillan Cancer Support
4. *The Cost of Cancer,* The Policy Exchange, 2010

'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)

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 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.

The recently published 2014 National Cancer Patient Experience Survey (in England) includes a number of findings that support the requirement for the introduction of an initiative such as one-to-one support, for example:

• 71% 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

• 59% of patients said that hospital staff gave them information about how to get any benefits to which they may be entitled
• 61% of patients reported that they were definitely given enough care and help from health and social services after leaving hospital – a figure that has declined by 1% in each of the last two surveys
• 63% 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 22% of patients said they had been offered a health assessment and care plan – a slight decrease from the high of 24% recorded in the 2012 survey

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.

1.2 Living with cancer as a long-term condition

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[5]:
- 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.

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.

'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, 20111)

5. *Cancer Follow-up Care: the views of patients and carers*, Picker Institute, 2008

1.2.1 Health and wellbeing amongst cancer survivors

Wellbeing is a broad, multi-element concept that is a composite measure of many different elements of a person and their health and happiness. Although not a new concept, it is becoming an increasingly important policy driver and the Office for National Statistics is now tasked with measuring the UKs national wellbeing. A recent Department of Health publication[6] highlights the importance of wellbeing and why it matters to health policy. The document emphasises that health (and mental health in particular) is viewed as a top priority. Specifically, there is a strong correlation between wellbeing and:

- adding years to life
- improving recovery from illness
- is associated with positive health behaviours in adults and children
- is associated with broader policy outcomes
- influences the wellbeing and mental health of those closest to us
- affects how staff and health care providers work
- has implications for decisions for patient care practices and services
- has implications for treatment decisions and costs
- affects decisions about local services
- has implications for treatment decisions and costs
- may ultimately reduce the cancer burden

Furthermore, there is also a strong correlation between wellbeing and improved recovery from illness, including:

- a greater resistance to developing illness (people who have a tendency to experience negative emotions report more unverified health complaints[7])
- lower wellbeing is associated with slower wound healing

6. *Wellbeing: why it matters to health policy*, 2014
7. *Emotional style and susceptibility to the common cold*, Cohen, Doyle, Turner, Alper and Skoner (2003)
8. *The impact of emotional wellbeing on long-term recovery and survival in physical illness: a meta analysis*, Lamers, Bolier, Westerhof, Smith and Bohlmeiier (2012)
9. *Cured – but at what cost?* Macmillan Cancer Support, 2013

- those with high wellbeing are more likely to recover and survive from illness (patients with high baseline levels of wellbeing were 1.14 times more likely to recover and survive from an illness than those with low baseline levels of wellbeing[8])

There is significant and growing evidence that there are significant and long-term consequences of cancer and its treatment. A recent Macmillan report[9] draws together much of the evidence of the long-term consequences that can result from a cancer diagnosis, including:

- the impact of having cancer often does not end when treatment finishes
- around one in four of those who have been diagnosed with cancer face poor health or disability after treatment
- the long-term consequence of cancer and its treatment include both physical and mental effects such as chronic fatigue, sexual difficulties, mental health problems, pain, urinary and gastrointestinal problems, and lymphedema
- many of these problems can persist for at least 10 years after treatment and can be significantly worse than those experienced by people without cancer
- certain treatments for cancer also increase the risk of other serious long-term conditions such as heart disease, osteoporosis, or a second cancer
- the impact of cancer and its treatment affects much more than just health. There are many wider implications that have a significant impact on the person and their wellbeing including social isolation, financial worries caused by disruption to work, and the potential impact on education and future prospects for those who are treated for cancer as children or young adults

- some consequences of cancer can be reduced with simple interventions, while more complex issues require more specialist services

There is also a growing body of evidence that describes and quantifies the impact that a cancer diagnosis can have on mental health. A recent study published in the Lancet (August 2014), reported that 6% to 13% of people affected by cancer had clinical depression, compared to just 2% of the general population at any time. Therefore, someone living with cancer is between three and six times more likely to experience clinical depression, but 75% of those reporting these symptoms were not receiving any treatment.

In addition to having significant implications for wellbeing and quality of life, the same study found that the relative risk of mortality increased by 17% in cancer patients with depression compared to those without depression.

The current 'medical model' of cancer treatment is very heavily focused towards physical wellbeing and is achieving significant improvements in survival rates. However, advances in medicine and treatment can also often make the 'cancer story' much more complex and more difficult to provide adequate support for. It is also clear that it requires a different blend of skills and expertise, stretching beyond the medical, treatment focused model that currently prevails, to effectively support those who have had a cancer diagnosis to recover fully from the disease and treatment.

1.2.2 The role of person centred care

The concept of person-centred care continues to gain prominence and has the potential to significantly impact on health and social care systems. Shared decision making and self–management support are two of the key elements that underpin person-centred care. A recent Health Foundation report highlights the significant impact that these can have on wellbeing and effectively supporting people to live with long-term conditions[10]. The report also highlights that while person-centred care has become one of the major goals of health policy on all four countries in the UK, slow progress has been made towards achieving its implementation.

Additionally, the ongoing increase in demand for healthcare services, coupled with a challenging financial climate – has propelled the issue of large-scale transformation of services from important to imperative. This will require a reorientation of services away from traditional, paternalistic models of care to an approach focused on prevention, empowerment and pro–active management, with the underlying premise being that – over time – these models will be more efficient. This presents a challenge for commissioners as the success of person centred care relies on improving integration across and between health and social care services, with the result that financial savings are realised by this approach are likely to be spread across these sectors.

Domain 2 of the NHS Outcomes Framework focuses on enhancing the quality of life for people with long-term conditions. As part of its work in this area, NHS England has developed the House of Care model to provide a framework for delivering person centred care for people living with long-term conditions.

The House of Care model recognises that managing long-term conditions is the biggest challenge facing healthcare systems worldwide, and that they account for 70% of health and social care costs in England[11]. The model itself places integrated person-centred care as the centre of any approach to tackle this problem, noting that the foundation of the House of Care is built on commissioning as a quality improvement cycle rather than basic contracting. The roof is built with the best organisational clinical processes, focused on implementing what we know works.

However, the most important changes for delivering and improving the management of long-term conditions are the pillars of the 'house':

- engaged, informed individuals and carers, and
- health and care professionals committed to working in partnership

The core principles of person-centred care are also captured in the NHS Five Year Forward View which includes a strong focus on empowering patients to gain greater control of their own care promoting better integration between different parts of our health and social care system.

Macmillan is currently working to identify, develop and implement the most patient and cost-effective solutions to deliver person centred care for people affected by cancer in the UK. The Macmillan Redesigning the System (RTS) programmes are piloting different approaches with partners to change the cancer system to ensure all cancer services in hospital and the community, providing medical, practical and emotional support are joined-up and designed around individual needs.

One-to-one support sits alongside and supports this wider system redesign work by piloting new ways of supporting people who have had a cancer diagnosis once they have completed their treatment.

It should be recognised that the contextual environment into which both one-to-one support and Macmillan's RTS work are being introduced is exceptionally challenging. NHS and social care budgets are under enormous pressure. The scale of this pressure was recognised by the new Chief Executive of NHS England Simon Stevens on his first day, stating that the NHS is 'five years into the longest period of austerity that the Health Service has ever seen'. Further factors that make the context particularly challenging include the lack of stability, reducing staff numbers and the reorganisation of NHS England. All of these factors are very likely to present additional challenges, have a negative impact on the development, implementation and sustainability of pilot programmes such as one-to-one support.

1.3 The cohort

A total of 15 sites were selected in two waves to participate in the Phase 1 pilot of One-to-One Support. The selection process took place in spring and summer 2012, with the aim of having two cohorts complete the pilot process in the summer and autumn of 2014. However, challenges in setting up the pilots – notably delays in the recruitment process – resulted in the timings of the pilots becoming very spread out. The first pilot site's initial two year funding period was completed in August 2014, while the final projects are due to complete their funding period in spring 2015.

10. *Person Centred Care: from ideas to action,* The Health Foundation, 2014

11. www.health.org.uk/news-and-events/newsletter/introducing-the-house-of-care

The map below provides an overview of the location and spread of the One-to-One Support pilot sites.

Figure 1.1: Overview of Location

South Eastern Health & Social Care Trust

Western Health & Social Care Trust

NHS Forth Valley

The Newcastle Upon Tyne Hospitals NHS Foundation Trust

Pennine Care NHS Foundation Trust

Care Plus Group

Betsi Cadwaladr University Health Board

Berkshire Healthcare NHS Foundation Trust

Aneurin Bevan Health Board

Ealing Hospital NHS Trust

Bristol Community Health North Bristol NHS Trust
South Gloucestershire Community Health Services University Hospital Bristol

Royal Marsden Hospital

University Hospital Southampton NHS Foundation Trust

Queen Victoria Hospital NHS Foundation Trust

Western Sussex Hospitals NHS Foundation Trust

The table on the next page provides an overview of the original configuration of One-to-One Support staff at each pilot site. It clearly shows the different makeup of the One-to-One Support pilot sites in terms of mix in number and type of each of the roles encompassed within the pilot, and this has further evolved as the pilots developed. It also shows the vastly different settings into which each One-to-One Support pilot site was situated (for example different health economy/home nation) and how the pilot sites are spread across a range of organisations located in primary, secondary and community care and integrated health and social care trusts. With this in mind, we would strongly discourage comparison between different sites, as each has had a different resource that has been hosted in a wide range of differing organisations and have faced distinct and differing challenges in the set up and operation of their pilot.

1.4 Individual contact demographics

This section looks at contact demographics, specifically gender, age and ethnicity who have accessed One-to-One Support. Figure 1.2 looks at the split of contact gender, while Figure 1.3 looks at the split of contact age. Figure 1.5 shows the ethnicity of patients, while Figure 1.5 shows the result, scaled to exclude 'Unavailable' ethnicity.

Figure 1.2 and Figure 1.3 show that the split of gender and age has remained fairly static throughout the scheme. Figure 1.2 shows that there is a larger proportion of female patients throughout the pilot: the average across all time points is 65.1% female, compared with 34.9% male. This differs from UK cancer population statistics, for which the split is 49.0% female to 51.0% male.

Figure 1.2: Split of Gender
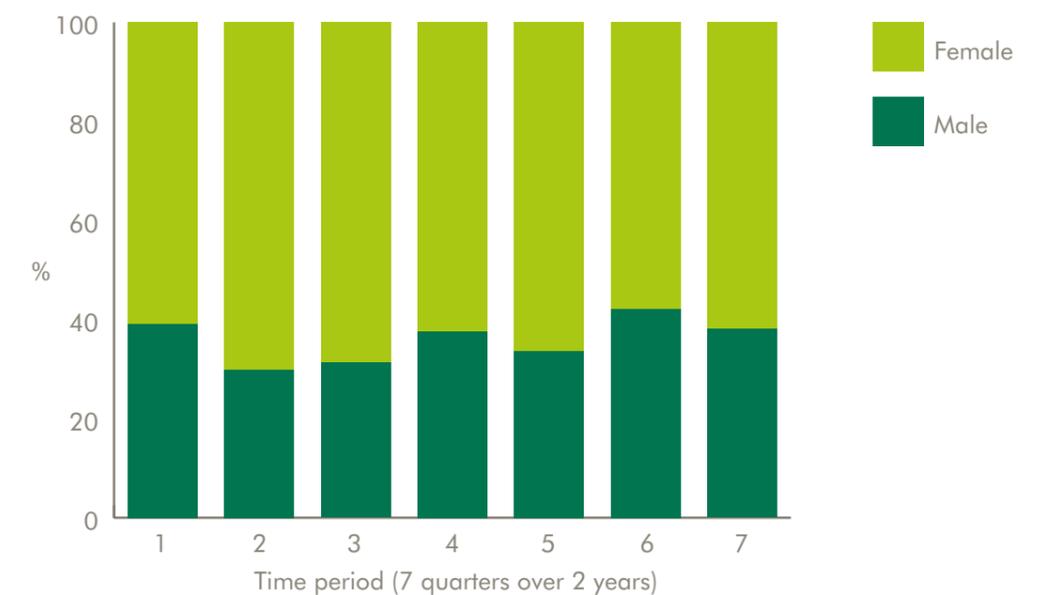
Table 1.1: Overview of Original Configuration of One-to-One Support Staff

Pilot Site	Macmillan Complex Case manager	Macmillan Nurse in Primary Care	Macmillan Nurse in Community Care	Macmillan Support Worker	Total number
England					
Bristol Integrated Cancer Services	2		2	3	7
University Hospital Southampton NHS Foundation Trust	1			2	3
Berkshire Healthcare NHS Foundation Trust	1			1	2
Queen Victoria Hospital NHS Foundation Trust, East Grinstead, Sussex	1			1	2
Newcastle-upon-Tyne Hospitals NHS Foundation Trust	1	1	1	1	4
The Royal Marsden NHS Foundation Trust	1	1	1	2	5
NHS Ealing	1	1	1	1	4
Care Plus Group, Grimsby, NE Lincolnshire	1	1	1	1	4
NHS Oldham (Pennine Care)	1	1		1	3
West Sussex			2	2	4
University College London Hospitals (UCLH)				4	4
Northern Ireland					
South Eastern Health and Social Care Trust			2	2	4
Western Health and Social Care Trust	1		1	1	3
Wales					
Betsi Cadwaladr Health Board		1	2	1	4
Aneurin Bevan Health Board	1	2	1	1	5
Scotland					
NHS Forth Valley			2	2	4
Total	**12**	**8**	**16**	**26**	**62**

Figure 1.4 overleaf shows the average split of age for One-to-One Support patients compared with the UK cancer population. As can be seen, generally patients who have engaged with One-to-One Support are younger than the UK average for cancer: There are greater percentages of Macmillan patients for ages 0–69 and fewer for age >70.

Overall contact ethnicity has remained fairly static throughout the scheme. The end of the pilot showed an increased percentage of patients of Afro-Caribbean descent; however this is likely to be a product of the lower number of forms returned for this time period. It is therefore clear that one area that the One-to-One Support pilots have not been successful in is engaging and working with people affected by cancer from diverse and representative communities.

Figure 1.4: Age Comparison with UK Population

Figure 1.3: Split of Age

Time period (7 quarters over 2 years)
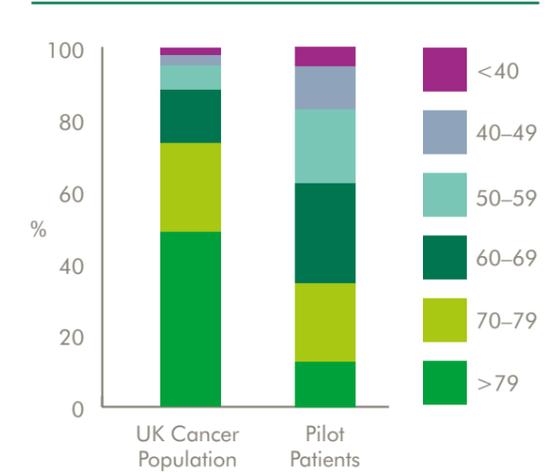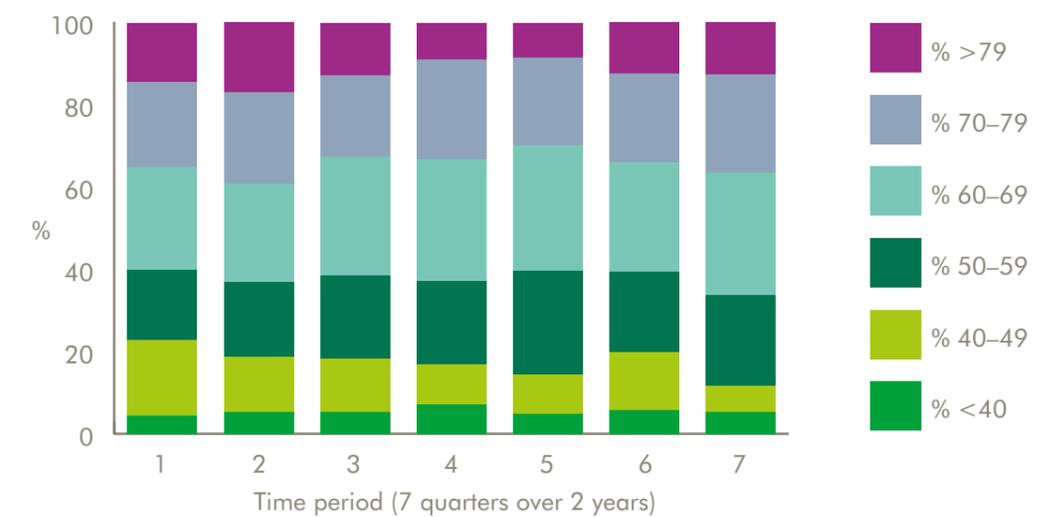
1.4.1 Method statement

The evaluation had two overarching aims:

- 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 Specifically, the objectives for the evaluation included:
- provide regular findings that help Macmillan to test whether the roles are fit for purpose (and provide the right model of care), and help Macmillan to achieve better outcomes for people with cancer
- draw out evidence and lessons learned on what works (and what does not work), for whom, why and in what circumstances – 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 with the pilot sites on a regular basis, including through the design and facilitation of four learn and share events

The evaluation process included the collection of qualitative and quantitative data. Specifically the primary methods of data collection included:

- qualitative data collection: qualitative interviews with One-to-One Support teams, the pilot leads and key NHS stakeholders at each site
- quantitative data collection: to capture evidence on the impact the introduction of the new roles has on the local healthcare economy, seeking to evidence the inputs, activities and outputs of the One-to-One Support postholders and the outcomes/impact on the local health economy
- patient survey: patient survey of those who have been referred, and whose care is being managed by, an individual in one of the One-to-One Support roles

Emerging findings from the evaluation were shared with Macmillan on an ongoing basis.

Figure 1.5: Reported Ethnicity
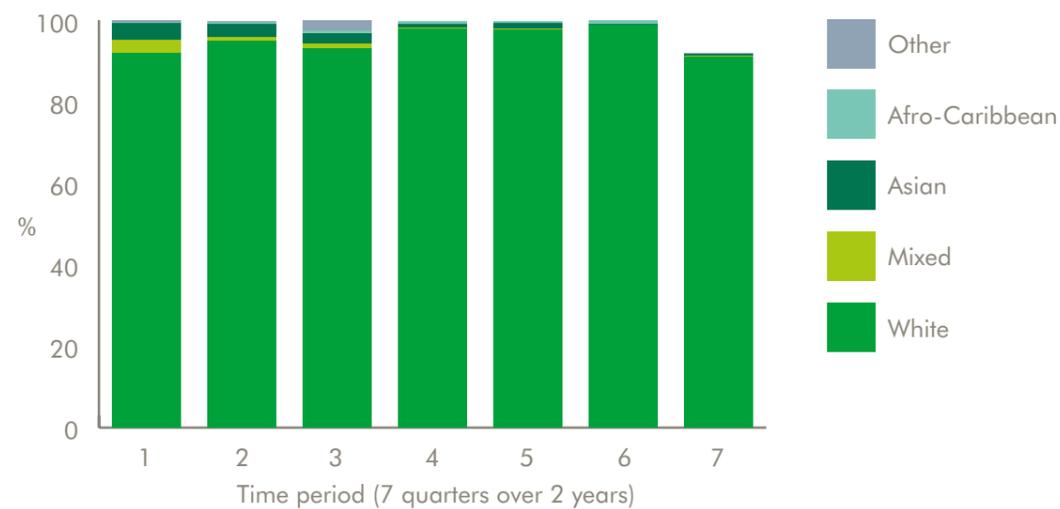
2

Postholder Activity Data

Throughout the evaluation postholders were asked to submit activity data on a quarterly basis using a bespoke data collection tool (an overview of the data collection tool is provided in Appendix 1).

Data collected included:
• days worked/lost in the period
• breakdown of time between patient facing/non-patient facing
• contacts made/location of contacts
• type of contact and nature of intervention provided
• aggregated age and ethnicity data for patients on caseload

The key findings from the analysis are presented below. Preliminary data cleaning was performed on the postholder data to ensure it was in the correct format and valid, and details of the data cleaning process are presented in appendix 2. It should be noted that the data presented below is the data returned by the postholders, and that the configuration of each team (e.g. the number of each type of role and the hours that they were contracted to work) differed across each team. This has an impact on the results presented below (for example the majority of returns were received from the support worker role). The graphs below show the results from seven time periods across the pilot to

demonstrate how the pilots changed as they progressed.

2.1 Days worked/lost

This section shows the overall working hours of Macmillan One-to-One Support post holders since initiation of the programme, extracted from the postholder data, in absolute terms (days) and as percentages. These results are shown in Figure 2.1 and Figure 2.2. The percentage of actual time worked, out of total time available for work, is shown in Figure 2.3. The reduction in the number of days worked over the course of the pilot (as shown in Figure 2.1) is attributable to postholders leaving/taking annual leave, therefore the total number of days available for work across the pilot reduced accordingly. Figure 2.3 clearly shows both the ongoing importance of Continuing Professional Development (CPD) in the development of the services included within the pilot, although it does reduce significantly from the early 'set-up' phase of the pilot to a lower figure as the pilot progressed.

Figure 2.1: Days Worked/Lost
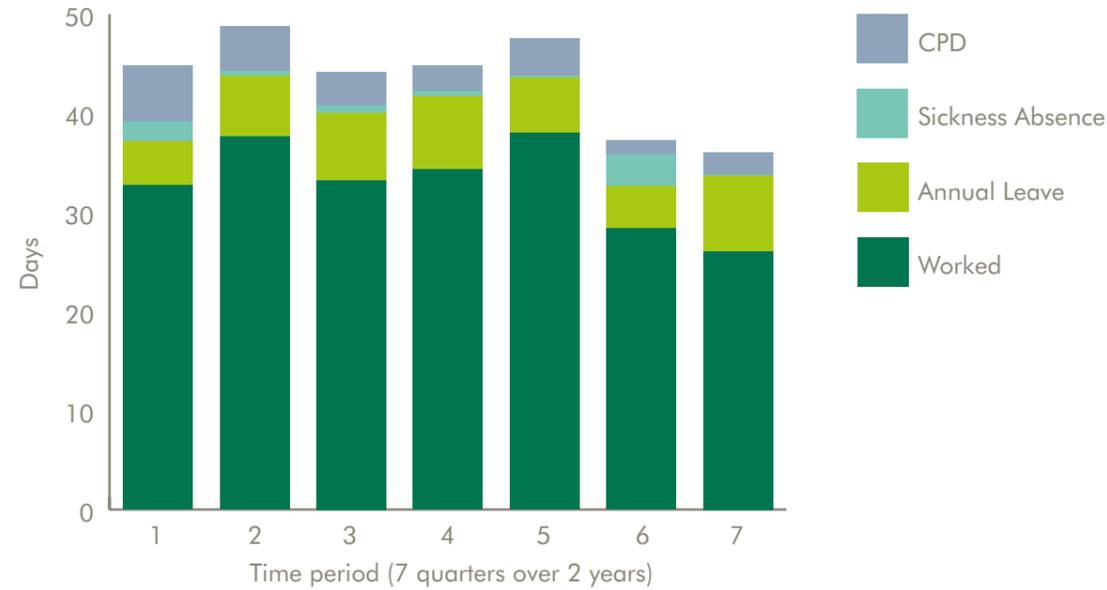
Figure 2.2: Days Worked/Lost (Scaled)
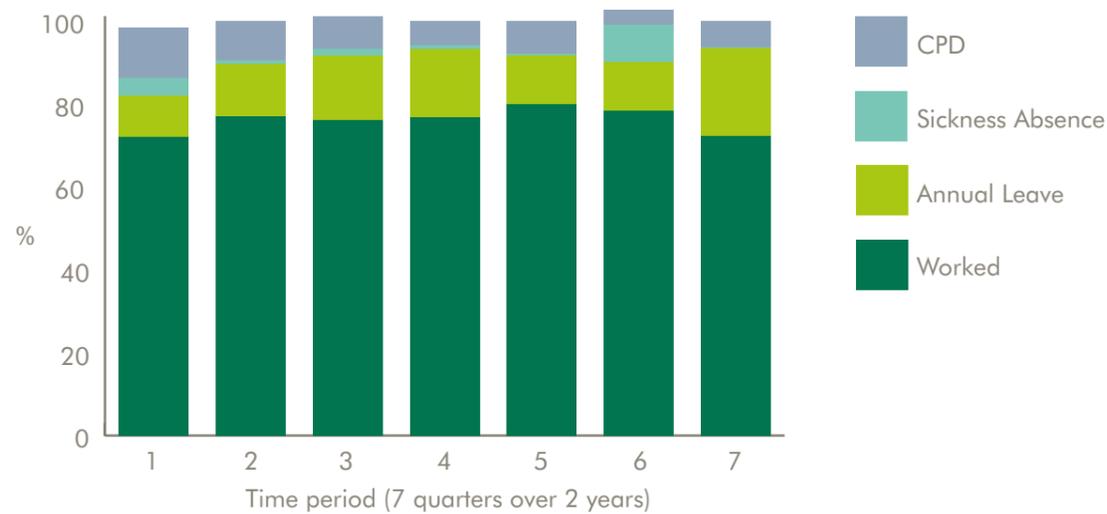
Figure 2.3: Days Worked (Time Available for Work)
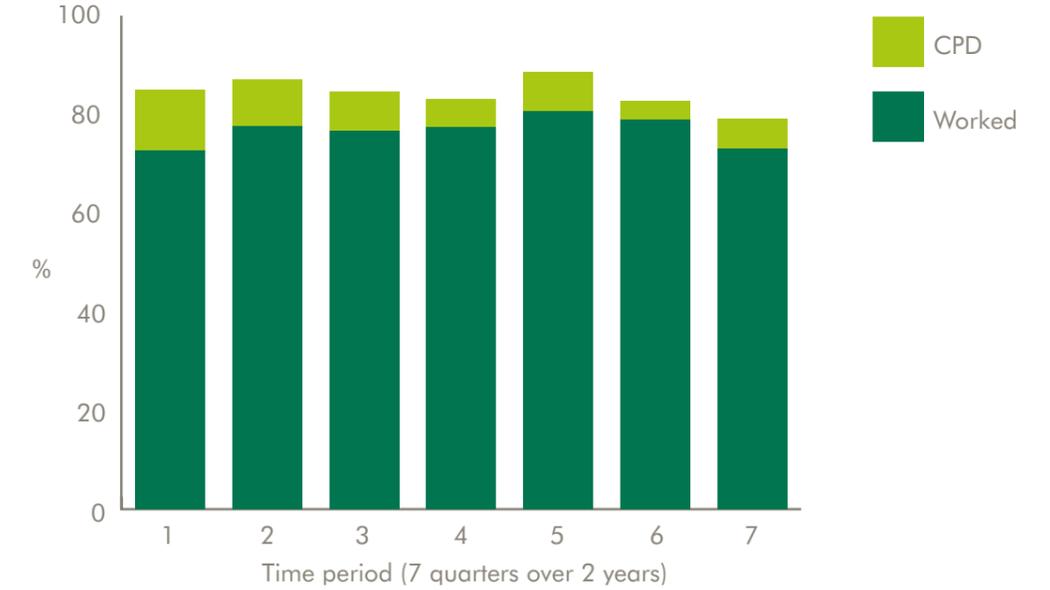
2.2 Split of time

The following Figure 2.4 presents the proportion of all possible splits of time, and Figure 2.4 extracts from this time specifically attributed to patient care.

The figure on the next page clearly shows the evolution of how the postholders have spent their time as the pilot has developed, with under 15% of time spend on direct patient care during the early development phase of the pilot, rising to just under 40% by the end of the pilot. By the end of the pilot, postholders were consistently spending over 60% of their time on work directly attributable to supporting patients (e.g. direct patient care, patient administration such as care plans and referrals, care co-ordination and patient education).

2.3 Individual patient contact types and outcomes

This section considers the split of different types of individual patient contacts and the outcomes from them. Contacts are either made alone or with another Health Care Professional (HCP) present. Figure 2.5 on the next page presents the split of contacts made alone or with another HCP and shows that by the end of the pilot, almost all contacts were made alone. Many of the joint contacts were with another member of the One-to- One Support team, hence the significant increase in contacts made alone as the pilot progressed, and the roles within the team became increasingly well established.

Figure 2.4: Split of Time

Legend (top to bottom):
- Average of General Administration
- Average of Travel
- Average of Working With External Stakeholders
- Average of Internal Team Meetings
- Average of Collecting/Inputting Evaluation Data
- Average of Providing Training/CPD
- Average of Receiving Training/CPD
- Average of Patient Education
- Average of Care Coordination
- Average of Patient Administration
- Average of Direct Patient Care

Time period (7 quarters over 2 years)

Figure 2.5: Contacts Made Alone/ With another HCP Present

- Average of % HCP
- Average of % Alone

Time period (7 quarters over 2 years)
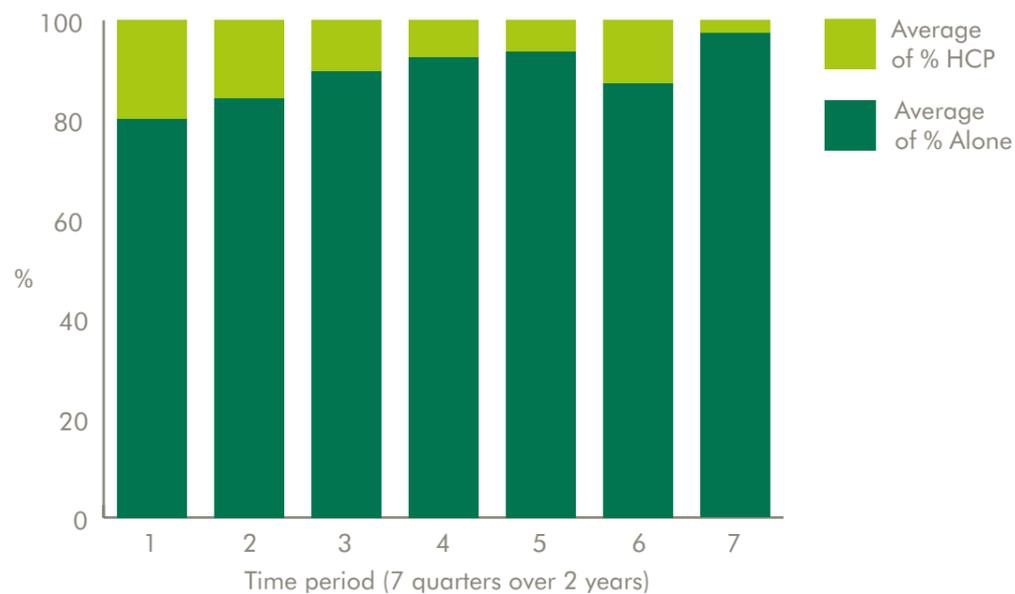
Figure 2.6 below shows the proportion of new to follow-up contacts undertaken by the One-to-One Support services. Unsurprisingly the proportion of new contacts decreased significantly as the pilot progressed. The proportion of new to follow-up contacts stabilised towards the end of the pilot at around 25%/75% which therefore may be viewed as what One-to-One Support services would be likely to deliver on an ongoing basis.

The volume of contacts made has also increased significantly as the pilot has progressed. Figure 2.7 shows that the average number of contacts made by each postholder has more than doubled since the introduction of the scheme, with an average of 106.9 contacts per month at the end compared to 52.4 contacts at baseline. This trajectory of the average number of contacts made per post holder continued to increase as the pilot progressed. As it did not stabilise, it is not possible to conclude what the upper ceiling of contacts made could look like for One-to-One Support services.

Across all time periods the majority of contacts have been made over the telephone or at home (Figure 2.8). Telephone visits have remained a fairly consistent proportion of total contacts, while the proportion of home visits has increased substantially from 22.1% at baseline, to 40.4% at the end of the scheme. By later stages of the pilot telephone and home contacts constituted a significant majority of all contacts, suggesting that patients are receiving care more suited to them. In–hospital contacts (Inpatient and Outpatient) are consistently low, particularly towards the end of the scheme, further reflecting this trend.

Figure 2.6: New/Follow-up Contacts

- Average of % Follow Up
- Average of % New

Time period (7 quarters over 2 years)
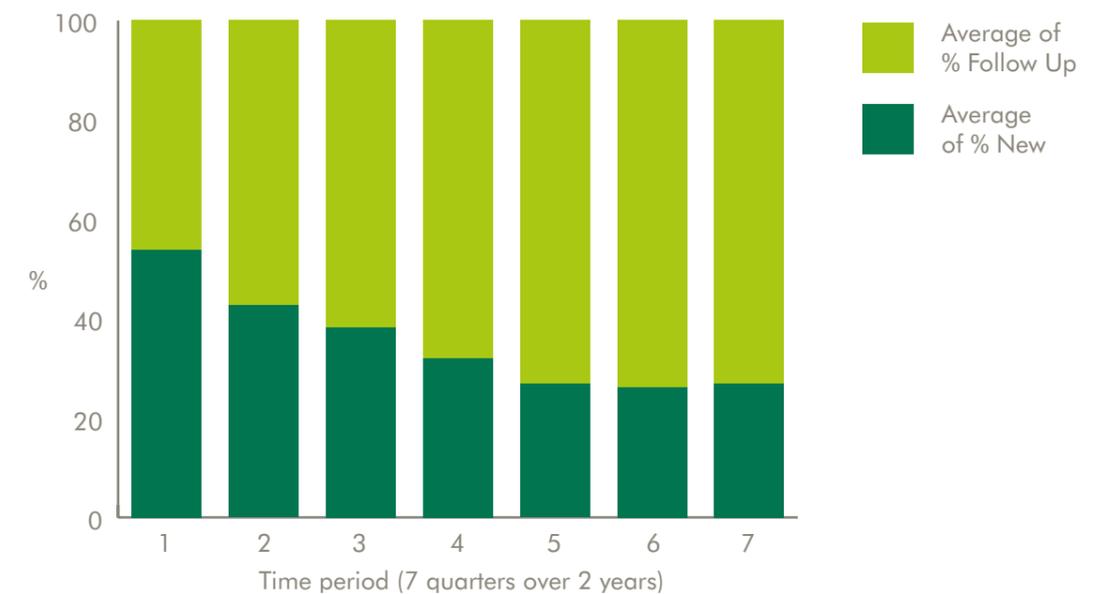
Figure 2.7: Average Individual Contacts Made

Contacts made vs Time period (7 quarters over 2 years)
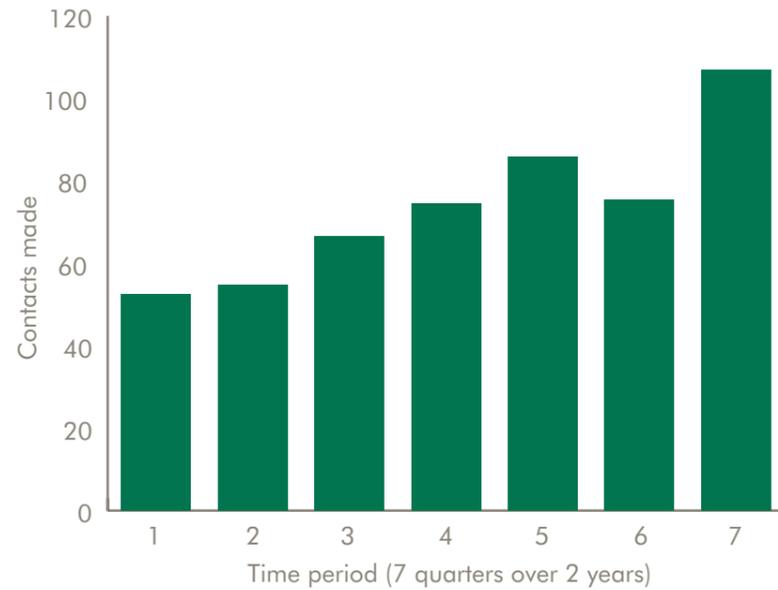
2.4 Nature of individual contacts

A substantial section of the form collected the outcomes that resulted from each contact between a One-to-One Support worker and a person who had been affected by cancer. This was split into ten possible responses:

• contacts with holistic needs assessment
• contacts with assessment and care planning
• contacts providing education, advice, support etc.
• contacts supporting self-management
• contacts with routine follow-up (for example working through issues identified in the holistic needs assessment and/or ongoing support)
• contacts with referral to other service
• contacts with test ordered
• contacts leading to discharge
• contacts leading to avoided hospital admission
• contacts with other outcome

Unlike the other parts of the data collection process with One-to-One Support workers, the responses here are not mutually exclusive. The number of each type of contact increased as the pilot progressed, which is likely due to the increase in number of contacts made, as shown in Figure 2.7 (above). The individual contact outcomes (see table 2.1) were weighted according to the actual number of contacts made during each data collection period, and table 2.1 shows the outcomes in order of percentage change from baseline.

Table 2.1 shows that the contacts providing education, advice and support have increased the most at 68%, followed by routine follow-up contacts at 58%, contacts with referrals to other services at 51% and contacts leading to discharge at 45%. Contacts with other outcomes decreased by 47% and contacts with holistic needs assessment by 37%.

Figure 2.8: Location of Contacts

Percent vs Time period (7 quarters over 2 years)

Legend: Other, Telephone, Home, Community, Hospice, GP surgery, Outpatient, Inpatient
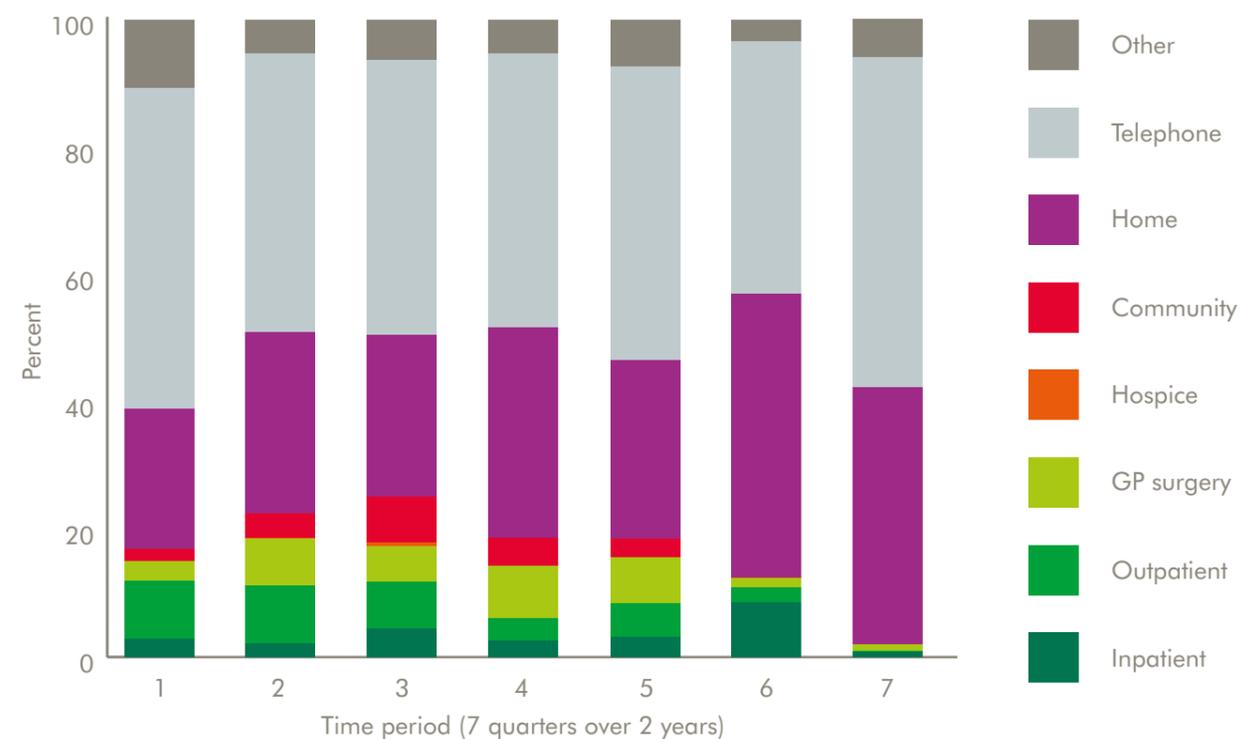
Table 2.1: Individual Contact Outcomes

	Time Period							Difference
	1	2	3	4	5	6	7	
Other Outcome	19.3	7.0	16.5	17.3	14.9	4.3	10.3	-47%
Holistic Needs Assessment	10.8	9.4	7.2	6.7	5.9	10.4	6.8	-37%
Assessment and Care Planning	12.2	9.1	6.2	8.9	8.6	13.5	9.2	-24%
Test Ordered	3.7	3.6	1.4	1.5	2.9	1.5	3.1	-16%
Leading to Avoided Hospital Admission	3.3	2.5	0.4	1.0	2.1	1.6	3.0	-8%
Supporting Self-Management	18.7	15.9	11.2	18.2	15.3	19.3	21.2	-13%
Leading to Discharge	3.2	4.5	1.8	2.1	2.6	5.6	4.7	-45%
Referral to Other Service	4.8	7.2	5.7	6.7	6.6	7.8	7.3	-51%
Routine Follow-up	11.4	14.3	9.0	13.0	13.6	22.4	17.9	-58%
Providing Education, Advice, Support etc.	16.5	24.1	21.4	27.1	20.0	31.4	27.8	-68%

The decrease in contacts with holistic needs assessment may be due to the increase in follow-up contacts, as discussed above. Similarly, this would account for the increase in routine follow-up contacts shown above.

The most common outcomes by the end of the pilot were providing advice, education or support; supporting self–management; and routine follow–up.

2.5 Group contacts

Data on group contacts were elicited, capturing information regarding:

- the total number of groups carried out per time period
- average number of participants per group
- average number of postholders per group
- average length of group
- primary purpose of group (educational/ workshop, community awareness raising, wellbeing event, self-management workshop or other)

Unfortunately, these data were very sparsely populated, such that no meaningful results could be obtained, comparisons made nor comparisons drawn. For this reason, group contact data are excluded from the present analysis with the result that the figures presented in this section are likely to represent an underestimate of the total contacts and subsequent outcomes delivered.

2.6 Individual contact need

Figure 2.9 considers the need level of patients, as described by the National Cancer Survivorship Initiatives Follow-up Risk Stratification process. This splits all cancer survivors into three groups:

- Level 1: Self-care with support – NCSI (The National Cancer Survivorship Initiative) suggest that between 70–40% of patients will fall into this category. As part of the aftercare plan patients will be given information about selfmanagement, 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 (Support Worker)/ CCM (Complex Case Manager) as an initial point of contact
- Level 2: 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
- Level 3: 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 (Multi-Disciplinary Team)/ relevant professionals. Cancer patients will be treated depending on which approach is most suitable, and the level of professional care will vary accordingly

Figure 2.9: Level of Follow-up Support

Time period (7 quarters over 2 years)

% Level 3
% Level 2
% Level 1
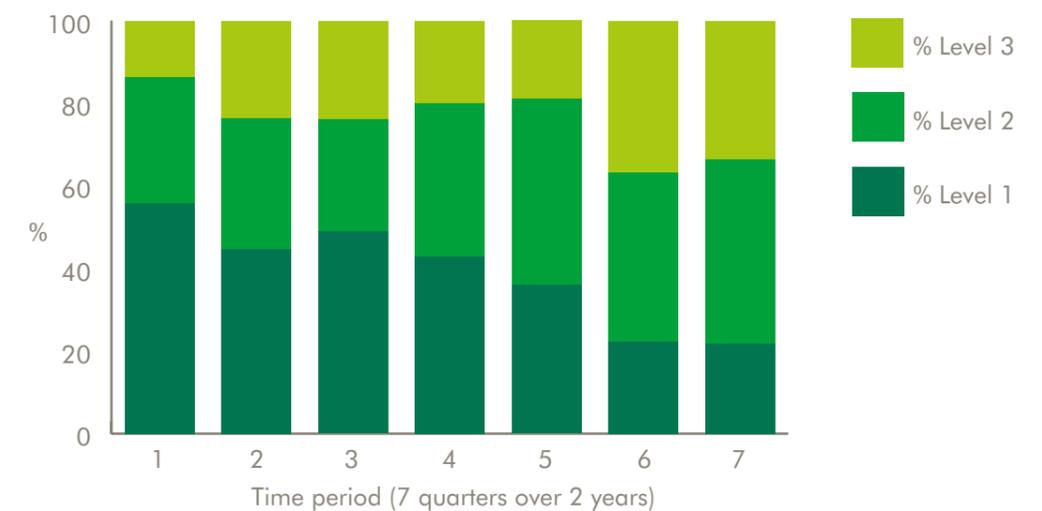
Cancer survivors may move between these different category depending on their disease, health status and individual needs. The proportion of people in each group will vary depending on the tumor type.

Figure 2.9 considers which of these levels best describe those people supported by the pilot. By the end of the pilot just over 20% of patients of the One-to-One Support pilots supported were categorised as level 1 (self-care with support), while just under 40% were level 3 (complex case management). This indicates that as the pilots progressed they did not work with a cohort of patients whose support needs were representative of the wider population of people who had been affected by cancer, but rather were working more with those who had greater levels of support needs. As people affected by cancer were either referred to the One-to-One Support pilots by healthcare professionals who were not part of the pilot (e.g. GPs or CNSs) or could self-refer it is likely that these latter

figures are representative of the cohort of people affected by cancer (and their level of need) who could benefit from and would access one-to-one support.

The proportion of the caseload for the One-to-One Support pilots who had complex support needs also increased significantly as the pilot progressed; from 13.7% at the start of the pilot to 33.7% by the pilot end. The percentage of level 2 patients has also increased from 30.5% to 44.4%, while level 1 patients have declined, from 55.8% to 21.9%. However this progression does indicate that patients are now receiving the most appropriate level of care based on their need (e.g. level 1 support worker, level 3 complex case manager).

2.7 Patient cohort by cancer site

Figure 2.10 shows that the split of patient cancer sites has remained fairly stable, which is a result of many of the pilot sites working with patients from particular sites. The comparatively higher proportion of breast cancer patients in relation to other cancer sites is worth noting in relation to the overall demographic data for the pilots as it has resulted in the pilot sites engaging with a greater proportion of females than males.

2.8 Quality of life data

Patients who accessed One-to-One Support were asked to voluntarily complete Quality of Life questions. Each patient answered the questionnaire once, at a time when their One-to-One Support was in place. All patients were asked to complete the EuroQol 5 Dimension questionnaire (EQ–5D). Table 2.2 shows the EQ–5D utility values by site.

EQ–5D results for Sussex are very high compared to other sites, at 0.738 compared to the mean for all sites, 0.523. Average scores for Aneurin Bevan, Western Trust, Forth Valley and Bristol are all below 0.5, the lowest score being Aneurin Bevan with an average of 0.399. This reinforces the significant differences in the way that each One-to-One Support pilot sites operates, and the typical support needs of patients each were able to access.

Figure 2.10: Patient Cancer Site
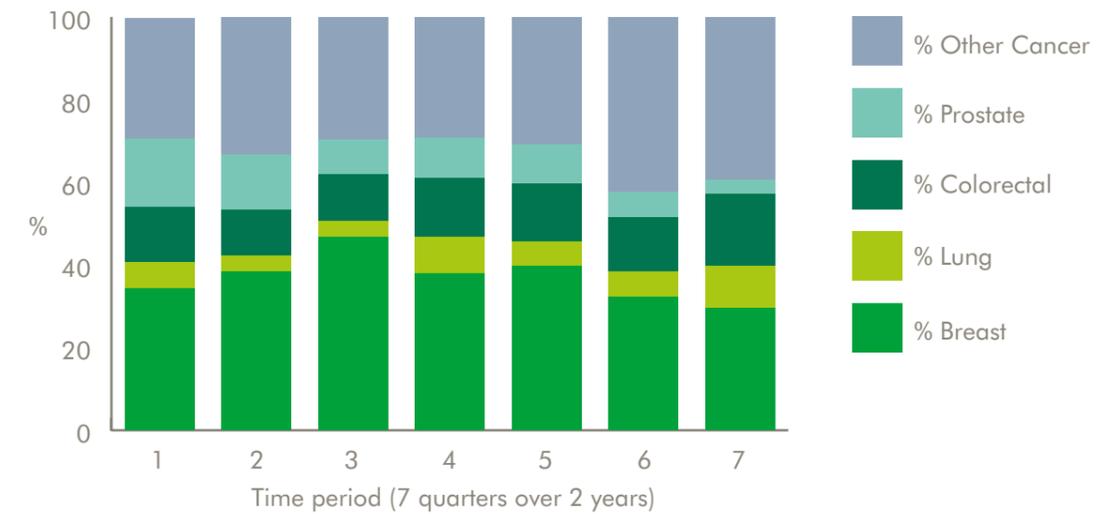
Table 2.2: EQ–5D Responses by Site (1.0 representing perfect health)

Site	Forms Returned	Average of EQ–5D
Aneurin Bevan	11	0.399
Berkshire	19	0.638
Betsi Cadwaladr	15	0.633
Bristol	19	0.466
Care Plus	11	0.570
Forth Valley	48	0.440
Newcastle	25	0.519
Oldham	14	0.540
South Eastern	22	0.586
Southampton	4	0.578
Sussex	3	0.738
Western	4	0.432
Overall	195	0.523

3 Feedback from One-to-One Support Pilot Sites

3.1 Site visit structure

This chapter presents an overview of the key challenges and learning that has emerged from a number of visits to each of the pilot sites. The site visits included indepth qualitative interviews with Macmillan One-to-One Support postholders, pilot leads and key stakeholders at each site. The key themes in terms of the challenges and learning in implementing, developing and sustaining models of one-to-one support are discussed below.

3.2 Setting–up one-to-one support

There were a number of common challenges that emerged in setting up the One-to-One Support pilots. Some of these provide valuable learning for Macmillan to inform its development and support for any future pilot processes, while others provide valuable learning to help inform future attempts to replicate one-to-one support. It is worth emphasising that each pilot site took at least three to six months to become what may be recognised as operational. This was due to a range of both anticipated and unanticipated reasons including induction/setting up the service (e.g. establishing protocols and practice)/building relationships with key stakeholders and gaining access to

people affected by cancer who could benefit from one-to-one support. Reflecting these challenges, many pilot sites are still working to increase referral numbers and achieve optimum caseloads one year post-commencement.

3.2.1 Project management and support

Many of the pilot site leads have been tasked with bidding for, setting up and managing the pilots on top of their existing workload. This led to several requests for additional resource from Macmillan to fund ongoing management costs of the pilots. While in many instances the host organisation has been able to manage the pilot effectively without support, a few sites have required additional support from Macmillan (in the main funded from regional budgets) to ensure that the pilots do not become isolated and are given the appropriate level of support. For those sites that had not had access to additional support, management of the pilots remains additional to the pilot leads' prior duties. Two key areas that have been highlighted as potentially impeding progress of pilots are project management and administration support.

3.2.2 Recruitment and retention

Many sites were able to recruit effectively; some that offered the posts as fixed term contracts (as opposed to secondments) experienced greater difficulty in filling

the posts. This is because it is perceived as 'risky' to leave an existing job in the current economic environment. As the pilot progresses, there is a risk that postholders begin to leave their posts for other, more secure jobs. This is likely to remain a risk as long as the sustainability of the posts remains in doubt. As many of the posts were also part-time, this added to the difficulties in recruitment. Over the course of the pilot a number of posts have been adapted to full-time posts, and there have been 13 resignations so far (representing 10% of posts in the pilot). One site has to date been unable to recruit to one of their posts but is continuing to work to do so.

3.2.3 Recruiting the right skills for a pilot
Recruitment focused heavily on the required clinical skills, along with assessing candidates' understanding of the needs of cancer survivors. Many postholders have confidentially reported being surprised at the level of service development and promotion that has been required, particularly at sites where recruitment has proved to be more challenging. While many have embraced the challenge, they have also indicated that they have had to develop these skills 'on the go' and would have benefited from both being aware that this was a requirement of the role, and support to develop and refine the appropriate skills. Future Macmillan service redesign programmes may wish to consider providing greater prominence to service development and promotion (when advertising posts), building assessment of these competencies into the interview process, and providing support (training) to individuals and teams once they are in post.

3.2.4 Physical space and facilities for the service
Several sites reported that they did not have an allocated physical space (i.e. a room/desk) or access to appropriate facilities (a computer/telephone/printer) during the early stages of the pilot. In addition to making them feel 'unwelcome', it did on occasion contribute to difficulties in promoting the service as they could not produce materials or leave contact details with people affected by cancer or stakeholders. While physical space in facilities is a challenge in many NHS facilities, it may be that Macmillan should consider including appropriate allocation of space as part of future bidding processes to ensure that resources achieve maximum impact and are able to 'hit the ground running'.

3.2.5 The power of the Macmillan brand
The Macmillan brand is powerful, and for many stakeholders (and families of those with a cancer diagnosis) it has strong connotations with palliative care. This has led to both stakeholders, people affected by cancer and carers, making assumptions about the type of support that the new services offer, and who should be referred to them. It has on occasion also had an impact on recruitment, where despite the job description clearly articulating that the roles are about survivorship, this has not been picked up by applicants. Collectively, this highlights the power of the Macmillan brand and the extent to which there is still work to do to change perceptions about the organisation and its role in supporting people affected by cancer.

3.3 Relationships key to success

Building effective working relationships with key local stakeholders has been vital to the success of the One-to-One Support pilots. Where this has not taken place it has had a significant impact on the performance of the pilot, notably in relation to gaining access to people affected by cancer and generating caseloads.

There have been varying levels of support for each of the pilots across the country. Some have had very active support from a GP or senior clinician, who has had a significant impact on smoothing the implementation of the pilots and overcoming any local resistance. Those who have not had the same level of support have faced significantly greater difficulty in raising awareness of the service. Although progress has been made in overcoming this challenge, it has taken significant time and effort on the part of the postholders (and often support from the pilot managers and Macmillan Development Managers).

Feedback from the pilot sites indicates that, where appropriate senior clinicians (most often Clinical Nurse Specialists) have been involved in the application to be a pilot site, along with designing and managing the service or the postholders, working relationships have been much smoother. This has helped to ensure that those stakeholders are clear on the aims of the pilot, how it differs from existing provision and indeed helped

them to better understand the needs of people affected by cancer once they have completed active treatment. It has also helped with professional reluctance to let go of 'patients'. Anecdotal evidence suggests that resistance from existing services in engaging with the One-to-One Support teams has been stronger where existing services are being, or are likely to be, reviewed, which has resulted in existing clinical staff perceiving the introduction of One-to-One Support as a threat.

The roles being piloted as part of the One-to-One Support pilot also differ significantly from the type of posts that Macmillan has traditionally supported, including what they are trying to do, how they are trying to do it, and the variety (in terms of banding) of staff that are involved. This has led to Macmillan Development Managers (MDMs) having to work through different challenges at a local level than they have been used to. Specifically, this has meant developing relationships with new providers and developing understanding about community services and how they work – a process that has taken time. They have also faced a challenge in increasing the awareness and understanding of survivorship amongst managers and healthcare professionals, including the challenges that face people affected by cancer once they finish their treatment, and an absence of existing service provision to address these challenges.

3.4 Lower than anticipated referral rates

The challenges of implementing the pilots, described above, have, in turn, led to lower than anticipated referral rates at many of the sites, and a longer than anticipated lag in generating referrals. Where stakeholder relationships have not been quickly and effectively established, there has, in some instances, been active resistance to the introduction of the posts. Feedback from One-to-One Support staff at sites that have experienced this challenge point to a range of factors, including resistance to passing the care of 'patients' to someone else and/or apprehension that the new service poses a 'threat' to existing services or clinical roles.

The experience of the pilot sites to date has also emphasised the importance of establishing effective communication early on, as once these relationships have been damaged, they are very hard to reestablish.

It is important to emphasise that the lower than anticipated referral rates are unlikely to be the result of people affected by cancer not having a need for the type of care and support offered by the One-to-One Support pilots. Indeed, early feedback from people affected by cancer (presented in chapter 3) supports the research that underpinned the One-to-One Support model – specifically that they have care and support needs following treatment that often are not addressed by existing models of care and support. Rather, a number of other factors have led to the smaller than anticipated caseloads, including:

- challenges setting up and establishing the service (described above)
- an early focus on ensuring that One-to-One Support services were not inundated with requests for support that they were unable to manage, for example by limiting access to the service

to people affected by a specific type of cancer and/or a specific geography (several pilot sites expanded or removed these criteria towards the end of the pilot which is likely to have a positive impact on caseload numbers). This would indicate that the early focus at several pilot sites on protecting against demand outstripping supply for access to One-to-One Support is likely to have underestimated the wider challenges of setting up a new service, thereby unnecessarily further limiting the number of people affected by cancer who were able to access the service

- referral rates have been further suppressed where referral to the new service has been limited by geography (i.e. to people affected by cancer who are registered at a specific practice). This has been attributed to either busy staff in primary or secondary care not having the time to check if a specific person is registered with an eligible GP practice (and therefore not referring anyone) or viewing this as a type of 'post code lottery' for people affected by cancer and subsequently choosing not to refer to the pilots
- existing clinicians gatekeeping for people affected by cancer. Many of the pilot sites had sought to establish protocols that would result in people affected by cancer accessing the service via a referral from existing clinicians (e.g. CNS or GP). However, in many instances this did not lead to patients being referred to the new service. Instead, several sites have piloted working with GP practices to access their cancer registries and write directly to individuals who are identified as having had a cancer diagnosis within a defined timescale (e.g. within the last five years). This approach has resulted in significantly more people affected by cancer coming forward with previously unidentified and unmet support needs, indicating that existing healthcare provision is not effectively identifying the support needs of care survivors

3.5 The four new cancer roles

3.5.1 Support worker roles

In most of the pilot sites the support worker roles have been well received. There are two principle ways in which the roles are being used:

- directly with CNS/teams of CNS to enable them to manage a bigger caseload by taking some of the less clinical/administrative areas (often including supporting people affected by cancer to complete a holistic needs assessment) of work and triaging calls to CNS; this has often been particularly beneficial in supporting change in patient follow–up by supporting the delivery of 'business as usual' while new processes are established and embedded
- working with community based One-to- One Support teams in a similar capacity by supporting the complex case managers/community care nurses/primary care nurses

Early indications are that these roles help CNS to manage a bigger caseload by taking on some of the less clinical and specialist areas of work as well as offering people a single point of contact and continuity. Where they have been working directly with CNS teams, the roles have been very well received and most appear to be well positioned to be supported by local commissioners. Where the support worker roles have been located in community based One-to-One Support teams, their prospects for pick up by commissioners have been directly linked to the likelihood of the community based One-to-One Support teams being picked up by commissioners (i.e. the support worker role in the community is only likely to be picked up as part of the whole team).

The role of healthcare support workers in general has recently received much discussion following the Mid Staffordshire NHS Foundation Trust Public Inquiry (chaired by Robert Francis QC) which recommended the creation of a registration system for any and all individuals (including Health Care Support Workers) who provide direct physical care for patients under the care and treatment of a nurse or registered doctor. It also recommended that a uniform code of conduct should be created that would apply to all HCSWs, and that the General Medical Council should prepare and maintain this along with appropriate education and training standards. The absence of clear guidelines on the training, responsibility and accreditation of support workers has led to uncertainty in this pilot in terms of what the posts can and should deliver, and has in turn led to many of the support worker roles undertaking different tasks/duties and having a different blend of clinical/administrative roles at each pilot site.

Despite this, the support worker roles have evolved well at each site, working effectively in a range of different ways (although it should be noted that the support worker roles in this pilot were mostly recruited to at band 4 (of the NHS Agenda for Change pay rates) which is higher than most traditional support worker roles.

3.5.2 Macmillan Primary Care and Macmillan Community Care nurses

The shared care roles, namely the Macmillan Primary care and Community care nurses, have not been so easy to get established. Initially referrals and caseloads were generally small but grew steadily and the majority of needs identified have been for emotional and practical support. However, a first assessment may take one to two hours to complete (not including dealing with any referrals) and it is unlikely that there is capacity within existing community services to undertake this.

Feedback highlights the importance of protecting this time as it enables nurses to build relationships and trust with patients and consequently surface and assess the challenges each individual faces. Whilst it is hoped that offering this service will improve patient experience and quality of life, there is a question about whether designating specific posts is a cost effective model (i.e. will result in savings across the health and social care system), or whether development programmes to enhance the skills of generalists might be a more impactful solution. There was also initially some tension within GP practices at some of the pilot sites, where practice nurses (who have tightly defined appointments and busy caseloads) perceive the Macmillan Primary Care Nurse roles as having an 'easy time of it' because they have smaller caseloads and more time to spend with patients. This has in turn led to pressure from some GPs for the Macmillan postholders to contribute to the wider business of the practice and fill any empty timeslots with patients who have not had a cancer diagnosis and would normally see the practice nurse.

3.5.6 Macmillan Complex Case Manager

There have been some concerns with the Complex Case manager roles, as in most cases there has been little to differentiate this role from the shared care roles (Macmillan Primary Care/ Community Care Nurses) in terms of clinical complexity. There is therefore no clear definition across the pilot of what constitutes 'complex', and concerns have been expressed by several senior postholders around their ability to maintain their competencies as required to retain their registration.

The main differentiator in this role to date is that the Complex Case Manager has often taken on some/all of the role in managing the team, reducing the burden on the pilot lead. This has been vital to the performance of the pilots, although discussions with some commissioners suggest that it is likely that once the One-to-One Support services become established and embedded, they would be likely to use less highly qualified staff when commissioning the roles on a substantive basis (i.e. the posts, if commissioned, would be at a lower banding).

There were some early signs that the One-to-One Support services were beginning to deal with more complex patients as caseloads across the teams increased. The pressure of full caseloads began to force teams to consider the adoption of a more robust approach to allocating people who access the service to the team member with the most appropriate skills.

Feedback from the Complex Case managers highlights that people affected by cancer do not like to be referred to as 'complex', and several therefore do not use this title with the people affected by cancer that they work with.

3.6 Awareness and understanding of survivorship

Qualitative and quantitative feedback gathered through the evaluation has highlighted the significant amount of previously unidentified emotional and psychological support that people living with and beyond a cancer diagnosis require.

It can take a significant amount of time and effort to surface these needs, and they have often not been picked up in a secondary care setting (even where the individual has access to a CNS).

Feedback from GPs who are involved in the pilot also highlight that they are not picked up by GPs (in a five minute consultation) or by district nurses (who often do not feel qualified to tackle any issues related to cancer, and do not have time during a time bound slot to surface and address the psychological support needs of people living with and beyond a cancer diagnosis).

However, there is a perception amongst some in secondary care that these issues are picked up by community staff, and they therefore view this pilot as duplication. This has not only had an impact on the referral of people affected by cancer to One-to-One Support, but is likely to present a challenge in ensuring the sustainability and any further roll out of One-to-One Support.

3.7 Responding to a gap in support for palliative care patients

A number of pilots identified that they were supporting individuals with a palliative prognosis, but who were not meeting criteria for specialist palliative care. Many of these individuals had emotional support needs but had been unable to access any other support. While supporting this group of individuals was not one of the original aims of One-to-One Support, it has surfaced a significant gap in provision in existing health and social care services.

3.8 Leadership and organisation of the project

A number of factors supported leadership and organisation of the project. In particular, the appointment of a project manager, who had a strategic and overarching role, had a positive impact. These individuals worked effectively to support the line managers (although where the project management role was adopted by the a member of the One-to- One Support team this presented a number of challenges, including their lack of pre-existing relationships with senior strategic leaders and diverting their attention away from the operation of the One-to-One Support service).

The early development of protocols and pathways; such as referral criteria, discharge policies, telephone clinics and streamlined paperwork, led to greater understanding of the service for all and effective functioning. Where staff were located in the same geographical area or co-located, this aided effective working and communications. The staff also felt less isolated and team working was more evident. This also enabled the development of clinical supervision/ action learning, which supported staff development and working.

3.9 Influencing future commissioning

An on-going challenge for the pilots remained effectively influencing commissioners to pick up and support them in the future. This may be compounded by the pilots' role in surfacing previously unidentified and unmet emotional and practical support needs – something which commissioners of health services are reluctant to address in the current economic climate.

This was also directly linked to the extent to which commissioners and senior influencers have a detailed and sophisticated understanding of the needs of cancer survivors and the extent to which these needs are/are not well served by existing health and social care provision. A further confounding factor which was the ongoing and extensive restructuring of commissioning organisations in England which will require the pilot sites and Macmillan to develop relationships with and influence a new group of individuals.

It is also clear that one-to-one support is well aligned with providing care and support in the community and building stronger links between health and social care, which is a clear direction of travel in each of the four home nations (e.g. the Better Care Fund in England, Transforming Your Care in Northern Ireland). It is also a strong example of patient centred care. However, that one-to-one support is not cost effective in the short term (i.e. will initially cost health and social care services more to deliver) continues to present a significant barrier to commissioning. At the time of reporting, three pilot sites are part way through the commissioning process to have all or part of the support picked up within local commissioning budgets.

Four sites have been granted interim funding from Macmillan Cancer Support to further test and develop the roles (and a further two are being supported by their regional Macmillan organisation to further develop and test the roles). One site is looking at taking the learning from the One-to-One Support pilot and exploring other more cost effective methods of delivery. The three pilot sites will not be taking forward any form of one-to-one support at this time and it is too soon to know what the outcome will be for the last 2 pilot sites that have established services.

4

Feedback from People Affected by Cancer who have Accessed One-to-One Support

The research included the production and distribution of a survey to explore, across all sites, the impact that access to a One-to-One Support worker/team had on people affected by cancer. Reflecting the slow start experienced by many of the pilot sites in generating a caseload during the early stages of development and implementation the response to the survey was initially limited.

To date we have received 229 completed surveys and the key findings are presented below. Of this number, 184 were completed by people affected by cancer who were in active treatment or in remission, and 45 were completed by people with a terminal diagnosis.

The quotes presented throughout this section are from people who had accessed One-to-One Support.

4.1 Demographics

The majority of respondents (68%) were over the age of 61. 22% were between the age of 45–60 and just 5% were 35–44. No one was under 35. 68% of respondents were female and 32% male. The majority (96%) where white.

4.2 Cancer type and status

The One-to-One Support teams are working with not only cancer survivors, but people across the full spectrum of cancer status. 35% of respondents reported that their cancer was in remission and that they remained well, with a further 36% reporting that their cancer was in remission but experiencing long term effects. 13% were in active treatment while 11% reported that they were palliative. 5% of respondents reported that they had engaged with the One-to-One Support team following the recurrence of a previous cancer diagnosis.

Breast cancer was the most common form of cancer amongst people who completed the survey, followed by colorectal and bowel cancer.

40% of respondents had been diagnosed 1 to 2 years ago, while 34% had been diagnosed 2 to 5 years ago. 12% had been diagnosed more than 5 years ago and 10% 6 months to a year. Only 2% had been diagnosed within the last 6 months (in line with the aim of One-to-One Support to provide support for people affected by cancer post-treatment).

4.3 Existing support structures

85% of respondents reported that family provided the practical support that they required prior to accessing One-to-One Support. 51% reported that they relied on friends and 22% said neighbours. 9% of respondents reported that they were regularly supported by 'another', including:

- cleaning lady
- council
- local cancer/support group
- work colleagues
- minister/church
- NHS/Macmillan Nurses

Respondents were also asked what type of support they relied upon others for. Social support was the most common response (58%) closely followed by transport (52%). 49% reported they received assistance with housework while a further 44% required help with cleaning and 37% with cooking. 34% required help with gardening and just 24% reported that they received help with personal care.

Figure 4.1: Cancer Type (N=229)
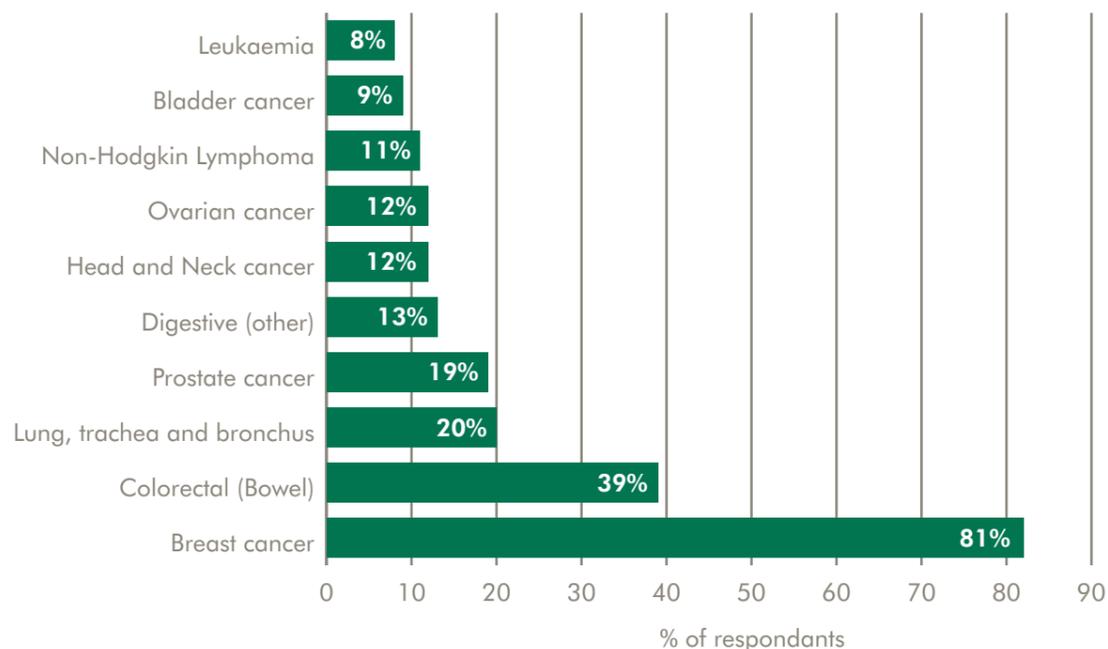
'My Macmillan worker helped me understand my feelings and emotions a bit more. They also helped me with the transition from being cancer patient to a more normal lifestyle and routine again.'

4.4 Concerns raised with Macmillan One-to-One worker

Respondents were asked to identify and report what concerns they had raised with their Macmillan One-to-One worker. The table below summarises the ten most common responses. It is clear from the range of responses that the One-to-One Support teams are responding to a wide range of concerns and issues that are being raised by people affected by cancer, many of whom are no longer in active treatment. The most commonly reported issue was 'tiredness/exhausted or fatigue' followed by 'worry, fear or anxiety', support to undertake 'exercise and activity' and 'sadness or depression'.

Other commonly reported concerns included:

- lack of access to support groups (31%)
- anger or frustration (31%)
- difficulty making plans (30%)
- how partner was coping (30%)
- diet and nutrition (30%)
- sweating (29%)
- lack of access to complementary therapies (29%)

Respondents were able to tick as many concerns as were relevant and on average respondents ticked 12 concerns. The table below shows the breakdown of number of concerns raised.

Table 4.1: Number of Concerns Reported

Number of concerns	No of respondents
0–5	62
6–10	49
11–15	48
16–20	34
21–25	18
26–30	8
31–35	6
36–40	3
41–45	2
46–50	1

Figure 4.2: Concerns Raised (N=229)

Concern	%
Tired/exhausted or fatigued	65%
Worry, fear or anxiety	52%
Exercise and activity	42%
Sadness or depression	40%
Eating or appetite	39%
Sleep problems/nightmares	39%
Getting around (walking)	38%
Pain	38%
Loss of interest/activities	37%
Memory or concentration	33%

% of respondents
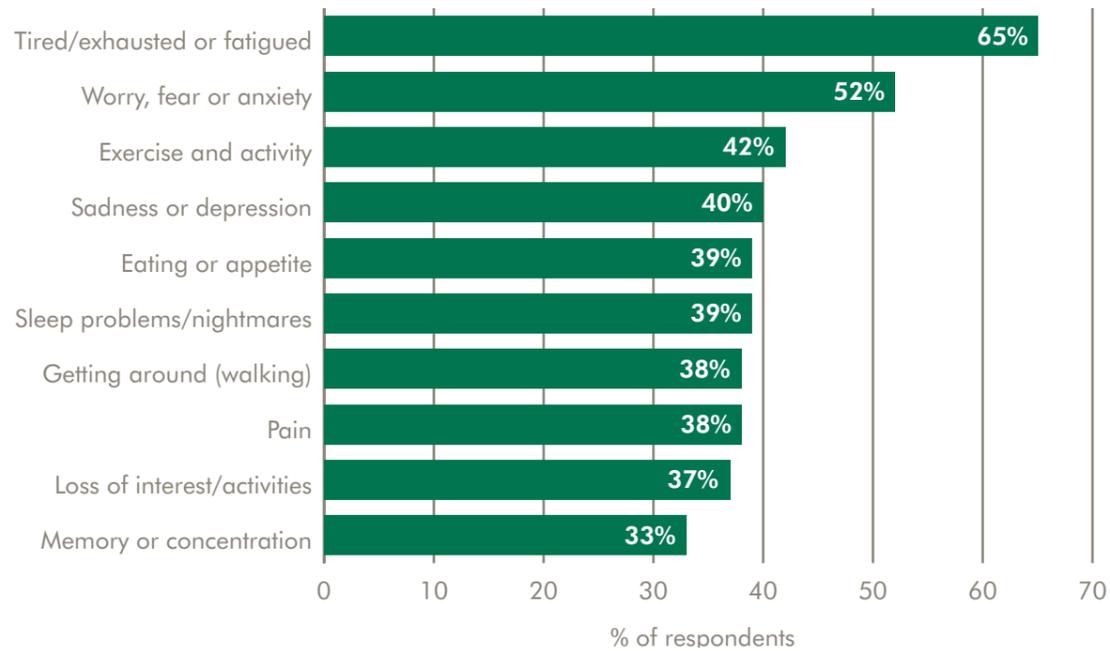
'My Macmillan worker has been able to provide advice, support and just someone to talk to. I can't praise her enough'

'I know that I can contact someone very easily. They are just at the end of a phone'

'They provided me with support and re-assurance, and I know she has contacts with me, my doctor and the hospital team I am under'

'Having support by phone cheers me up. Visits at home helps give me support as I have no one to talk too. I don't want to burden or off load on my 8 year old son'

4.5 Support received from One-to-One worker

Respondents were asked to use a scale of 1–10 to rate the overall quality of support they received from their Macmillan One-to-One Support worker along with a number of other factors (presented in the table below). It is clear that the vast majority of respondents rated their Macmillan One-to-One Support postholder very highly, and particularly valued their ability to communicate with them and the extent to which the Macmillan One-to-One Support postholder fully understood their needs.

It is interesting to compare this rate to the quality of support received from other healthcare professionals (excluding their Macmillan One-to-One Support postholder), where the average score was significantly lower at 7.7 (again using a scale of 1–10).

4.6 A catalyst for improving input from other healthcare professionals

It is clear that the One-to-One Support teams are building strong and effective relationships with people affected by cancer.

The majority (73%) of respondents reported that they felt that their Macmillan One-to-One Support worker had completely understood their needs while a further 21% reported that they understood them 'a lot'. Building on this, 88% of respondents reported that they felt that their Macmillan One-to-One Support worker understanding their needs had a direct impact on the quality of their care (a further 10% reported that they did not know if it had any impact, while only 2% reported that they felt that it had not had a direct impact on the quality of their care).

Table 4.2: Support Received

Macmillan One-to-One Support postholder	Overall quality of support you have received from them	Their knowledge of your condition	Their ability to communicate with you	The extent to which they fully understand your needs
1	1	-	-	-
2	-	1	1	-
3	1	1	2	2
4	-	2	-	2
5	2	4	2	4
6	4	2	2	3
7	12	13	8	5
8	22	22	8	18
9	14	20	20	19
10	162	151	173	162
Average score	9.3	9.2	9.5	9.4

Furthermore, 85% of respondents felt that their Macmillan One-to-One Support worker had helped other healthcare professionals to understand their needs 'completely' or 'a lot', while only 13% of respondents indicated that they felt that their support worker had little or no impact on helping other healthcare professionals to understand their needs.

"She has been able to explain in plain language about things I have not fully understood"

"The Macmillan team gave all me all the literature on my cancer so I was able to understand everything and have a more knowledgeable, conversation with the consultants"

"She discussed all the treatment options, answered all my questions and explained the after effects without trying to influence my decision"

'Reassurance from my Macmillan worker has increased my confidence and self-esteem enabling me to ask and discuss anxieties and concerns I had with regard to my treatments'

4.7 Increasing involvement in planning care and treatment

Respondents were asked to give their views on their level of involvement in planning their treatment and support needs prior to engaging with One-to-One Support. It is clear from the responses that people affected by cancer have experienced a high degree of variance in this regard. 32% of respondents felt they had quite a strong involvement and 30% felt they had some involvement. 28% indicated that they felt they had been completely involved in planning their treatment and support, while 9% felt they had not been involved at all.

This is another area where the One-to-One Support teams appear to be having a significant impact, with 71% of respondents reporting that following engagement with the Macmillan One-to-One Support worker they felt that they were 'completely' involved in planning their care and support or involved 'a lot'.

"I feel a greater sense of participation, therefore it is easier to comply with treatment plans"

"My input was always listened to and my care discussed with me prior to it commencing. I was treated as an individual and my needs and worries were taken on board and worked through"

4.8 Referrals

Respondents were asked what other services their Macmillan One-to-One Support worker had referred/provided them with access to and a summary of the top results is provided in the table overleaf (respondents could tick more than one answer).

Many are being referred to the Macmillan Information and Support Service, followed by benefits/financial advice services and physical activity/healthy lifestyle support services.

Comparison with the concerns identified and raised with the Macmillan One-to-One Support worker would indicate that many of the One-to-One Support services are directly supporting people to address concerns about tiredness/ exhaustion/fatigue, along with emotional and psychological support, but referring individuals on to other services (where they exist) for information, practical and financial support.

This aligns with feedback from the One-to-One Support postholders who report that community psychological and emotional wellbeing services are not universal, often have strict referral criteria and long waiting lists. Furthermore where provision does exist, it most often is targeted at people with higher levels of psychological distress.

"Helped me understand my feelings and emotions a bit more. Also helped me with transition from being cancer patient to more normal lifestyle and routine again"

Figure 4.3: (N=229)
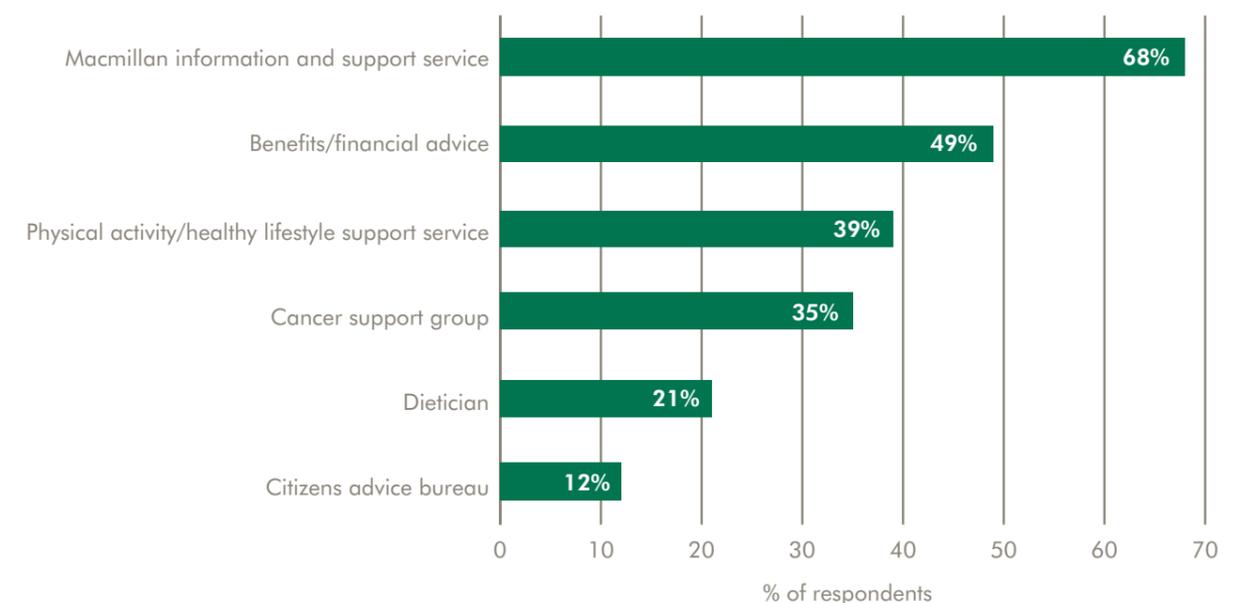
% of respondents

4.9 Improving support after treatment

71% of respondents indicated that they had received appropriate care and support following completion of their treatment, with a further 19% reporting that they were not sure if they had received appropriate care and support. The chart below shows the proportion of people who think they would have received appropriate care and support without the support of their Macmillan One-to-One Support worker.

It is clear that 42% of respondents indicated that they would not have received appropriate care and support without the support of their Macmillan One-to-One Support worker and a further 33% were not sure if they would have. Only 25% felt that they would have received appropriate care and support without access to One-to-One Support.
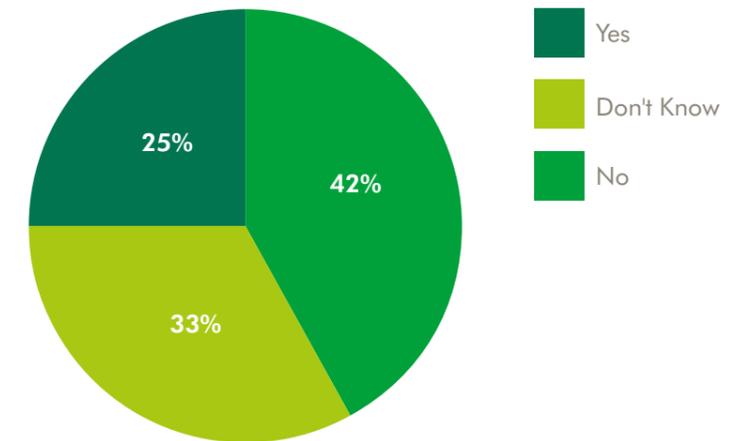
The results are more pronounced in relation to supporting people affected by cancer to deal with the consequences of their cancer/treatment, with 72% of respondents indicating that they felt that they had received appropriate support to enable them to deal with the consequences of their cancer and treatment.

However, of these, 55% indicated that they felt that without the support from their Macmillan One-to-One Support worker they would not have received appropriate support, and a further 27% were not sure.

Only 18% of respondents indicated that they would have received appropriate support to deal with the consequences of their cancer/treatment without access to a Macmillan One-to-One Support worker.

'I am able to talk about my inner most feelings. My Macmillan worker has encouraged me to meet new people at our meetings. I go out more with friends. She has encouraged me to take more exercise. She has helped me when I have been troubled about my treatment by contacting the healthcare professionals to explain fully what is happening to me.'

Figure 4.4: Do you think you would have received appropriate care and support without the support of your Macmillan One-to-One Support worker? (N=128)

- Yes — 25%
- Don't Know — 33%
- No — 42%

Figure 4.5: Do you think you would have received appropriate support to deal with the consequences of your cancer/treatment if you had not had access to a Macmillan One-to-One Support worker (N=163)

- Yes — 18%
- Don't Know — 27%
- No — 55%

"Introduced me to disability allowance, something which I did not know about or did not think I would be eligible for"

"Knowing information is available – through booklets and 121 telephone service. Can access things – I now know who to ask!"

"The Macmillan team have taken a lot of stress out of my day to day life. They are someone to talk to who knows what they are talking about"

"They helped me to not feel so isolated following surgery. Their visits always help me feel valued and confident even on my 'down' days… it makes me realise I am not going it alone"

"I am more confident & open about things, and it is reassuring to know I can talk to someone in a relaxed way"

"My Macmillan worker has been a constant line of support to me. She has been on hand to assist with my return to employment and guide me through the emotional upheavals that come with it. She has directed me to the right channels for financial benefits and assisted with referrals to various clinics within NHSS. A constant line of support and I would be lost without her. "

"The support has enabled me to deal with practical changes to my body following treatment as well as emotional impact of this on my day to day life"

The table overleaf provides a breakdown of the extent to which the Macmillan One-to-One Support worker supported people affected by cancer with specific aspects of support. It is clear from the responses that access to One-to-One Support is

supporting people across a wide range of areas, notably helping them to access and understand information, make decisions about their treatment and care, and manage the physical, emotional or practical impact of their cancer. One-to-One Support is having less impact (although is still effectively supporting a number of respondents) in supporting friends and family of people affected by cancer.

4.10 One-to-One Support – addressing the needs of people affected by cancer?

The majority of respondents (89%) indicated that following access to Macmillan One-to-One Support they had no further support needs. Of the 11% who indicated that they had further support needs that had not been met, the majority of unmet needs related to waiting times to be seen by a specialist or other healthcare professional and were not directly related to the intervention delivered by the Macmillan One-to-One Support worker.

4.11 Benefits of having access to a One-to-One Support worker

The picture below provides an analysis in illustrative form of the key words used to describe the main benefits that people affected by cancer ascribe to having been provided with access to a Macmillan One-to-One Support worker. The tool analyses the written statements that respondents made to identify the most commonly used words and create a picture that presents and scales each word depending on the number of times that it was used.

Table 4.3: How has your Macmillan worker helped/supported with the following (%, N=varies)

Macmillan worker	Not at all	A little	A lot	Completely	Don't know
Helped you to understand this information	1%	9%	26%	60%	4%
Helped you to access good, timely and accessible information	1%	6%	33%	54%	6%
Supported you to manage the emotional impact of your cancer	2%	8%	31%	53%	5%
Supported you to manage the physical impact of your cancer	3%	10%	30%	49%	8%
Supported you to manage the practical impact of your cancer	5%	9%	30%	47%	8%
Supported you to make decisions about your treatment and care	6%	10%	24%	45%	15%
Helped people around you to understand what living with cancer is like	17%	11%	20%	30%	22%
Supported your family/friends to access emotional, financial and practical support and information	20%	12%	16%	28%	23%

"Knowing that after treatment and hospital appointments there is still someone you can contact for help and information. Also the one to one Macmillan support lets you talk about your concerns and makes you feel that you're not left to struggle on yourself"

"My daughter could not understand my mood swings and feelings of fear, having to deal with cancer plus major surgery and chemotherapy which causes rows and friction between us. (My Complex Case Manager) explained everything to her, eased her worries and helped her to understand the situation which helped myself and my daughter greatly"

4.12 Thematic analysis of patient case studies

In addition to the patient survey, a number of One-to-One Support pilot sites submitted patient case studies. To protect patient anonymity, the case studies were analysed thematically focusing on three key areas:

• their concerns prior to accessing one-to-one support
• type of support accessed through one-to-one support, and
• the impact this had on them

The results presented below are based on the thematic analysis of 42 case studies.

4.12.1 Concerns prior to accessing One-to-One Support
The case studies provided details on how the person was feeling before any intervention. Worry and anxiety were the most commonly identified concerns. Most commonly people were worried about how they would cope with:

• their treatment (both ongoing and subsequent consequences)
• finances

• family responsibilities (particularly who would look after the children)
• returning to work
• fear of recurrence

There were particular concerns around the financial implications of unemployment including limited funds, uncertainty if they could ever return to work and uncertainty regarding what life might be like if they were unable to work again. People were also worried about their mobility after surgery and/or treatment and how they would cope with day to day life. This often resulted in further concerns about recurrence and having to go through it all again. Living with uncertainty caused anxiety amongst many and this was further heightened for those with children, often worrying about their future and how they would cope/who would look after them. There were also concerns for spouses and their ability to cope or responsibilities to other family members.

This state of worry and anxiety often left patients feeling scared and sad with many reporting poor mental health. Some patients reported strong feelings of sadness or hopelessness and despair, while others noted loss of interest in everyday life and activities – no longer wanting to see friends, family or participate in social activities. People also reported that things that were once enjoyable were now no longer of interest.

In addition to this, many were also experiencing physical side effects from the cancer and/or its treatment. Fatigue, nausea, tiredness and pain were some of the physical concerns affecting their quality of life. They described their fatigue as leaving them unable to do the simplest of tasks, leaving them feeling socially isolated and often with low self-esteem. This was also linked to issues of body image as a result of surgery, weight gain

and loss of hair. Others were struggling to come to terms with added physical changes in their appearance after cancer treatment.

Anger and resentment were other common emotions experienced by people affected by cancer prior to accessing One-to-One Support. They often felt frustration, loss of control, and anger/lack of trust in the NHS. Many felt that they had not received sufficient support around diagnosis and treatment, particularly emotional support, while others were resentful that this was happening to them and restricting their daily life. Some felt frustration that cancer was 'getting the better of them'.

4.12.2 Support accessed through One-to-One Support
The case studies then detailed what support patients accessed through One-to-One Support. Emotional support was key. As highlighted above, many patients struggled with the emotional aspect of their cancer diagnosis and found having someone there to listen to their concerns hugely beneficial. Empathy and understanding were seen as crucial aspects of the emotional support. Many reported that having that constant person there to speak to, run questions by and just vent frustrations to was invaluable.

Having someone independent (i.e. not a family member) to tell their story to without worrying about upsetting them or their feelings was perceived as vital aspect of the effectiveness of One-to-One Support – indeed often it was about having that time and space to help them come to terms with what was happening to them. One-to-One Support also referred people on to various other services such as support groups, financial aid and exercise/dietary groups. This practical support helped address many of

the patient's physical concerns. Examples of other services that the Macmillan workers refer onto included:

• Bristol Buddies – provides people affected by cancer with practical help around the home
• Care and repair – offers advice and assistance to enable people to repair, improve or adapt their homes
• Citizens Advice Bureau
• Dietician/ NBT nutritional programme and information service
• HOPE course – uses positive psychology evidence – based activities, such as goal setting, action planning, mindfulness and gratitude diaries, to create an upward spiral of positive emotions leading to improved confidence, social support, happiness and well-being
• Macmillan Benefits Advisor

The One-to-One Support teams were acting as the point of contact/link to other services, ensuring that the patient received the most appropriate care and support. They were often seen as the link between the family and other healthcare professionals, helping the patients to understand and digest information that was given to them and alerting them to other services and additional support.

They were seen as a useful source of information, providing booklets, advice and an understanding of symptoms and how to effectively manage these in addition to signposting and referring. Some of the more specific areas of support being provided by the one to one support workers included:

• confidence building
• financial grant support
• support to return to work
• relationship support

The One-to-One Support teams also helped people to set goals and take small steps towards improving their confidence and self-esteem. Actions ranged from organising wig appointments to referring onto counselling services or cooking and exercise classes. They provided information on grants and financial support (including crucially for childcare). People were also supported to return to work, with the One-to-One teams working to liaise with occupational health support and colleagues. Communication and counselling services were also promoted by the Macmillan workers to help improve people's relationships with their family and friends.

4.12.3 Impact on patient post intervention

The final part of the case studies details how people who accessed One-to-One Support felt after the intervention. Many felt supported and listened to, reporting reduced feelings of isolation and loneliness. Often it was about having that person with the time to listen – making the patient feel understood and valued. The One-to-One worker allowed the 'patient' the opportunity to talk about their personal fear, worries and problems without feeling like they were burdening anyone, with the Macmillan One-to-One workers often described as a 'safety net'. As a result, many were relieved of certain worries and stress including financial problems, returning to work, exercise and nutrition and had become more knowledgeable and informed.

This was often as a result of accessing services they would not have otherwise known about or been referred to. As a result of accessing One-to-One Support, many talked about following a healthy eating programme, taking up exercise and returning to work. It was not just people affected by cancer that benefited from One-to-One Support.

Many family members also noted the benefits that resulted from accessing One-to-One Support, for example spouses and family members felt better placed to support their loved ones and also noted improved understanding in both the physical and emotional symptoms their loved ones were experiencing. One-to-One Support also helped parents to help their children come to terms with the diagnosis, liaising with child psychologists and facilitating discussions around supporting them long-term. This included advice on how to explain to the child what was happening and/or preparing the child for the loss of a parent. Many people reported that they felt more positive overall and noted increased focus and motivation to get 'back in control of their lives'. Many were regaining confidence and independence to go out and get back to socialising and enjoying the activities they used to. Others felt they were more knowledge and as a result more proactive in managing their own care and needs.

Overleaf we present two case studies that are representative of the support that people affected by cancer received from the Macmillan One-to-One Support services. The individuals included in these case studies have provided their consent for their experiences to be presented in this report.

Case Study One

Mary was referred to the Macmillan One-to-One Project for assessment and support by her Clinical Nurse Specialist as she was worried that Mary was not turning up for appointments and on her last review had an infection and they were concerned about her ability to care for herself as her clothing was dirty.

Mary was diagnosed with cancer in 2010 and had radical surgery and reconstruction at that time. Her road to recovery was very difficult and she suffered from bladder and bowel problems, pain and walking difficulties. She had body image concerns and her physical relationship with her husband ceased to exist. Her husband left soon after. This affected her and she soon began to sink into depression. She felt lonely, isolated, hopeless, and guilty and had no interest in anything. Her grown up children live away and she had lost contact with friends. Mary had some input from the community psychiatric nurse until her depression was under control, but was then discharged and has felt unsupported since.

A year ago, Mary's cancer recurred and she awaits further radical surgery and reconstruction. In the year following her initial diagnosis and treatment she was also diagnosed with heart problems. Due to this she requires to be reviewed by the cardiologist prior to any anaesthetic being administered.

On the first visit by the Macmillan Community Care Nurse, Mary disclosed that the past year has been extremely difficult. Her depression has returned, she constantly asks the 'why me?' question, and her grandchildren had been taken into care. Even though she knew that she needed surgery as soon as possible she put her own health at risk in case her grandchildren needed her. Physically she knew that even if a call came she was not able to travel due to pain and discomfort. Sitting for any length of time was so uncomfortable for her. Mary had stopped caring for herself and her house was in a terrible state but she did not have the energy to do anything about it and did not know where to start or who to turn to for help.

Her Macmillan Community Care Nurse asked her to tell her story and invited Mary to complete a Holistic Needs Assessment to identify all her concerns and worries. Mary commented on the fact that her Macmillan Community Care Nurse had listened and not judged her.

As a result, Mary then disclosed that her inability to move about had resulted in rubbish piling up in the kitchen, and meant she was sleeping on the settee. Mary could not physically access the bath and her personal hygiene was also a problem.

Her Macmillan Community Care Nurse contacted various departments in social services, housing and local agencies to assist in clearing the house. A financial assessment was carried out, and a grant helped get the house repainted and had new vinyl flooring fitted. This gave Mary such a boost and for the first time in many, many months, Mary was out of pyjamas, in clothes and had done her hair and put makeup on. The GP was contacted and following assessment, he recommended her antidepressants. Her analgesics were also increased to control her pain and a repose pressure relieving cushion was requested to relieve the pain and discomfort when sitting.

The Macmillan Healthcare Support Worker was able to arrange clinic appointments so that she could accompany Mary and arranged transport to ensure she attended and had the important investigations she required to enable her surgery to go ahead.

The team have continued to support Mary and liaise with the clinical specialist nurses to ensure that surgery is arranged in the near future. Mary is now coping much better, her pain is controlled and she is managing to get out a bit more with the help and support. With encouragement Mary has kept in touch with her grandchildren by writing regular letters. Her grandchildren so enjoy receiving cards from their gran and sending cards back. This had cheered Mary up immensely. She now lives in a clean and comfortable environment and her self esteem and quality of life has improved. The team will continue to support Mary through surgery and on her road to recovery until she feels able to continue with her life independently and finds her 'new normal'.

Case Study Two

Tom's wife found out about the Macmillan One-to-One Project through a friend at work and phoned the team as she and Tom were at the end of their tether.

Tom was diagnosed with prostate cancer 4 years ago and had curative surgery at this time. Unfortunately Tom developed many problems post surgery which resulted in more hospital admissions. In 2013 he then required to have a hip replacement which unfortunately became dislodged meaning he had to have further surgery to correct this defect. Tom was no longer able to work and took on the role of house husband and caring for their 3 young sons.

These huge changes over a short period of time have taken their toll on Tom's mental health and when his Macmillan Community Care Nurse carried out a Holistic Needs Assessment his score was 8 – level 3 concerns. The Hospital Anxiety and Depression screening tool was also completed resulting in Tom being referred to the GP.

Tom admitted to being angry and frustrated as he had always worked. He felt useless due to his disabilities and inability to provide for his family. His relationship with his wife was also suffering emotionally and physically. He admitted to shouting at the children frequently as he gets annoyed easily when they don't listen or when they wake their Mum when she is on nightshift.

Tom was suffering almost constant pain. This limited any activities or outings. He felt he never had time for himself or to see his friends. Money was also very tight. Tom's Macmillan Community Care Nurse referred him for a financial assessment as he disclosed he was on the low rate of Personal Independent Payment. His Macmillan Community Care Nurse also carried out a pain assessment and she

explained how the analgesic ladder works as it was apparent that he was not taking his medication regularly or as prescribed. Following this explanation his understanding improved and his pain relief is under control.

Tom and his Macmillan Community Care Nurse agreed a Care Plan to encourage engagement in activities and seeing friends again. His Macmillan Community Care Nurse also suggested trying Cognitive Behaviour Therapy to explore his thoughts and feelings and how they impact on his physical symptoms. It was important to explain how feelings and behaviour are all interlinked.

Tom was able to see how one area affected another and with the help and support of his Macmillan Community Care Nurse was able to explore how he could break the cycle. He could see how his shouting was distressing for everyone concerned. Rather than shout at the kids, he now removes himself from the situation

by leaving the room. He was encouraged to be more involved with his children and take them out once a week.

Tom is now moving on with his life. His depression is lifting. He is on an antidepressant and being monitored by his GP. His pain is better controlled as he takes his analgesics on a regular basis. His relationship with his wife is greatly improved and he has made a promise to give her a kiss every day. Tom now spends quality time with his children and regularly takes them out to play football or to the park and they are enjoying life as a family again. He is now in control of his temper, removing himself from situations when he feels he is getting angry.

Life has meaning again and he now meets up with friends regularly. His Macmillan Community Care Nurse is now working towards discharging Tom as his concerns are almost resolved and his level of concern is now very low.

Cognitive Behaviour Therapy

Thoughts	Feelings
Kids will waken wife I can't concentrate They are annoying	Angry Frustrated

Behaviour	Physical (symptoms)
Shouting	Increasing heart rate Headache

Changes / care plan	
Asked to reflect on his childhood relationship with father Discussed children and attention seeking behaviour Will go into another room when noise is overwhelming Will take children out once a week	

5 The Economic Case – Changes at the Pathway Level

5.1 Cost effectiveness at the pathway level

The initial economic case for the introduction of One-to-One Support was presented by Frontier Economics in the Department of Health commissioned report One-to-one support for cancer patients (December 2010)[13]. The estimates included in the report indicated that the additional annual cost of providing one-to-one support to all people affected by cancer would be around £59.7 million (central estimate), which would be offset by the annual gross benefit to the NHS of £88.8 million (central estimate).

The patient level benefits, reaped due to the improved support offered to them, has not been quantified. The model of one-to-one support used to produce these estimates is very similar to that which is being piloted by Macmillan and its partners in this pilot, with a clear focus on using a team with an appropriate skill mix to:

- ensure personalised holistic assessment and care planning which takes account of needs associated with the individual, the disease and the treatment
- undertake a major role in coordination and continuity of care, through supporting people affected by cancer to navigate the system, to signpost to other sources of support, and ensure that they can re-enter the system if required

- ensure that people affected by cancer and their carers get information, advice and support about diagnosis, treatment, aftercare, palliative and end of life care services
- enable supported self-management, where appropriate
- identify emerging problems around communication between people affected by cancer and the healthcare system, symptom control and side effects of treatment, signposting to appropriate lifestyle interventions
- take a leading role in the provision of care and support, for example by providing specialist clinics as appropriate to the individuals needs

The estimates produced by the model illustrated that the costs of providing one-to-one support would be fully or partially offset by a number of the benefits arising from improvements in the quality and coordination of care (for example reduction in emergency bed days, reductions in routine follow-up appointments and GP visits).

The evaluation team therefore worked with each site to quantify the impact that introducing this type of support has had on the wider local health economy. This included the production of a bespoke tool to try and measure the quantifiable changes in healthcare usage that have resulted from the support provided to individuals by the Macmillan One-to-One

13. The full report can be accessed at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216683/dh_122521.pdf

Support teams. A full copy of the tool is provided in appendix 3. It aimed to capture data for the relevant catchment area and cohort of patients' in the pilot site, in aggregated form on:

- elective and non-elective admissions to hospital
- length of stay in hospital
- new and follow-up outpatient appointments to hospital
- consultant/nurse led outpatient clinics
- appointments with a GP
- contacts with existing community health services e.g. district nurses
- end of life care, including % of people dying at home.

There were a number of challenges in collecting the pathway level data and using it to make the economic case for one-to-one support. In terms of the collection of data, many of the pilot sites have found it particularly challenging to access data held by other organisations, for example if the pilot is hosted by a community or primary care organisation accessing data held by their partners in secondary care (and vice versa).

The comparatively small number of referrals received by the teams – and the time lag in generating caseloads that resulted from the challenges experienced by the pilot sites during set up – also mean that changes observed in the pathway level data that result from One-to-One Support are likely to be small. Furthermore, significant changes in both how pathway data was collected at several sites, and significant changes in how services were delivered, would have made it virtually impossible to attribute any changes at the pathway level to the introduction of One-to-One Support.

These challenges were compounded by the type of support that has been provided by the One-to-One Support

pilots (in response to need identified by people affected by cancer through the use of a holistic needs assessment). The feedback from the One-to-One Support teams (provided above and corroborated by the feedback from people affected by cancer who completed the survey) indicates that much of the support provided by the pilots to people affected by cancer is emotional, psychological or relates to providing referral or access to information and advice on social or financial concerns. This type of support is unlikely to have a significant impact on the reduction in access to the costly secondary care services that underpin the cost–effectiveness model developed by Frontier economics, but may be likely to have an impact on the use of primary and community healthcare services over the medium to long term (timescales which are outwith the scope of this evaluation).

The findings to date therefore suggest that while the One-to-One Support model is unlikely to generate savings in the short term (it is likely in fact to cost more money, with the exception of support workers who are working directly with CNS and are therefore improving efficiency of specialist staff), it is an effective means of meeting previously unidentified need, improving patient experience and quality of life, and potentially addressing many of the concerns raised by people affected by cancer in the national cancer patient experience survey.

5.2 Costs of providing One-to-One Support

The direct costs for piloting One-to-One Support at fifteen sites across the UK for two years was £2,925,56714. This funding (provided by Macmillan Cancer

Support) covered the cost of employing the Macmillan One-to-One Support postholders, along with funding for some other incidental expenses. Therefore this figure excludes a number of other costs, for example recruitment and the management of the One-to-One Support services and the physical space in which they were located (which were borne by the host organisation). The average cost of providing One-to-One Support per site for two years was £195,038, although this figure hides some significant variances in the actual cost per site (which ranged from £332,018 to £114,367).

It should be noted that these figures are likely to overestimate the annual cost per outcome/patient supported as they cover both the design, set-up and training of One-to- One Services and staff (with each pilot site taking at least six months to become fully operational).

None of the One-to-One Support sites in the pilot had reached full capacity within the pilot timescales, although the cohort showed significant growth in caseload and activity as the pilot progressed. It can therefore be assumed that the average cost per patient and interaction presented below would reduce as sites delivering the One-to-One Support services achieve full caseloads. One further caveat is that the figures below focus on individuals who have accessed One-to-One Support in the community. As several of the pilots progressed, the Macmillan One-to-One Support Workers moved to support change/expand capacity by supporting Cancer Nurse Specialists in secondary care settings. The figures below have not captured some of the people affected by cancer who received support in this setting due to the comparatively small nature of the support provided by the One-to-One Support Worker (the primary contact with the patient was delivered by

the CNS). Again, the figures presented below are therefore likely to represent an underestimate of the impact that One-to-One Support has had, and overestimate the cost per patient/interaction.

Evidence collected throughout the evaluation indicates that approximately 2,090 people affected by cancer received support from the community based Macmillan One-to-One Support. Therefore, the average cost of providing support per patient across the pilot was £1,399. However, given that many of the services did not build a significant caseload until they had been running for around six months, this figure is likely to represent an overestimate by at least 25%. Furthermore, as caseloads grew as the pilot progressed (and no service achieved full capacity) it is likely that the cost per patient would reduce further (and significantly) for fully established One-to-One Support services. Similarly, the cost per patient contact (total recorded contacts across the One-to-One Support pilot was 20,237) at £144.56 is likely to represent an overestimate as a result of the same factors discussed above.

Further evaluation of the One-to-One Support approach could therefore focus on quantifying the full value of the support provided (for example using a methodology such as the Social Return on Investment model) and identify and quantify potential savings in community and primary care. This may include exploring where One-to-One Support has the biggest impact, for example on people affected by cancer who face more (or less) complex barriers, more (or less) complex people who have been affected by cancer, and the association between mental health challenges and comorbidities in people who have been affected by cancer.

6 Conclusions and Recommendations

The One-to-One Support pilots faced a number of challenges in setting the pilots up and getting them established. Each pilot site took at least three to six months to become what may be recognised as operational. This was due to a range of both anticipated and unanticipated reasons, including induction/setting up the service (e.g. establishing protocols and practice)/building relationships with key stakeholders and gaining access to people affected by cancer.

This has had a knock-on effect in the number of people affected by cancer that the pilot sites have been working with – indeed no pilot site has been able to identify what a maximum active caseload for their One-to-One Support service would look like. Together, with the challenges in recruiting/starting the pilots (many had only reached one year post establishment by the end of 2013), this has resulted in there being a limited amount of data to work with for this report around what fully established, embedded and operational one-to-one support will deliver.

The success of each pilot has been directly related to the ability to build effective working relationships with key local stakeholders. Feedback gathered

through the evaluation indicates that where appropriate senior clinicians (most often Clinical Nurse Specialists) have been involved in both the application process to be a pilot site, and the design and management of the service or postholders, working relationships have been much smoother. This has helped to ensure that those stakeholders are clear on the aims of the pilot, how it differs from existing provision and indeed helped them to better understand the needs of people affected by cancer once they have completed active treatment. It has also helped to reduce 'possessiveness' of patients. This is supported by further feedback, where evidence suggests that resistance from existing services to engage with the One-to-One Support teams has been stronger when existing

services are being/are likely to be reviewed. This seems to have resulted in existing clinical staff perceiving the introduction of one-to-one support as a threat. Feedback from Macmillan Development Managers has also indicated that supporting the One-to-One Support pilots has required them to build new relationships and networks with key local stakeholders. Collectively, one of the key enablers of 'success' at each pilot site has been strong, committed leadership that has the ability to provide strategic cover – and influence – at a senior level, supporting the pilots to operate effectively, while making the case for future pick-up.

The four new roles encompassed within the pilot have been welcomed to varying degrees by existing healthcare provision. In general, the Macmillan Support Worker roles have been very well received, particularly where they support CNS to manage a bigger caseload/implement changes in patient follow-up in taking on some of the less clinical and specialist areas of work, as well as offering people a single point of contact and continuity.

The shared care roles have not been so easy to get established. Initially, referrals to the One-to-One Support services were low but grew steadily as the pilot progressed, and as indicated above, the majority of needs identified have been for emotional and practical support. However, a first assessment may take one to two hours to complete (not including dealing with any referrals) and it is unlikely that there is capacity within existing community services to undertake this. Feedback highlights the importance of protecting this time as it enables nurses to build relationships

and trust with people affected by cancer and consequently surface and assess the challenges each individual faces. It is clear that offering the One-to-One Support service is an effective means of implementing patient centred supported self-management and holistic care for people affected by cancer – and delivers improved experience and quality of life for people affected by cancer. There is however a question about whether designating specific posts is a cost effective model, or whether development programmes to enhance the skills of generalists might deliver some of the impact delivered by one-to-one support in a more cost effective way.

There have been some concerns about the long term sustainability of the Complex Case manager roles as, in most cases, there has been little to differentiate this role from the shared care roles (Macmillan Primary Care/ Community Care Nurses) in terms of clinical complexity. There is therefore no clear definition across the pilot of what constitutes 'complex', the main differentiator in this role to date is that the Complex Case manager has often taken on some/all of the role in managing the team, reducing the burden on the pilot lead. It is therefore likely that where the Complex Case manager role is retained it is likely to be at a lower band than once the service has been established and embedded.

The feedback from people affected by cancer who have received support from a Macmillan One-to-One Support worker has been extremely positive and reinforces the need for this type of support. Only 25% of people affected by cancer who have responded to the

survey indicated that they thought they would have received the appropriate care and support following the end of their active treatment, without access to their Macmillan One-to-One Support worker. Furthermore, only 18% indicated that they felt that they would have received appropriate care and support in dealing with the consequences of their cancer/ treatment without access to a Macmillan One-to-One Support worker.

One of the key findings to emerge from the survey of people affected by cancer who have accessed Macmillan One-to-One Support is the range and type of concerns that they raise with them. While tiredness and/or exhaustion is the most common concern, it is followed by worry/ fear/anxiety, eating and appetite, and sadness and depression.

In fact the ten most prevalent concerns raised with the Macmillan workers are a blend of health, social, and psychological care issues. This presents a challenge in relation to where the pilots should be located/funded in the future as they do not easily fit into the existing (and often separate) health and social care structures (although they do help to achieve better integration from the patient perspective by navigating the different elements of our health and social care system on the patients behalf). Therefore this may present a timely opportunity given the drive for better integration across health and social care and Macmillan may wish to consider exploring ways to incorporate or align the pilots with these ongoing initiatives (e.g. the Better Care Fund).

As many of the One-to-One Support pilots moved into their final year of Macmillan funding, they faced

an ongoing challenge to influence commissioners to pick up and support them in the future. This has been compounded by the pilots' role in surfacing previously unidentified and unmet emotional and practical support needs – something which commissioners of health and social services are reluctant to address in the current economic climate. This has also been directly influenced by the extent to which commissioners and senior influencers have a detailed and sophisticated understanding of the needs of cancer survivors and the extent to which these needs are/are not well served by existing health and social care provision. Where this has been overcome, it has often been down to strong, committed leadership from the pilot lead within the host organisation and the tireless work of the One-to-One Support teams. Therefore, there continues to be a significant role for Macmillan to continue to educate commissioners on the challenges affecting people affected by cancer following their active treatment.

The feedback from the One-to-One Support teams (corroborated by the feedback from the survey of people affected by cancer who have accessed One-to-One support) indicates that much of the support provided by the pilots to people affected by cancer is emotional, psychological or relates to providing referral or access to information and advice on social or financial concerns. This type of support is unlikely to have a significant impact on the reduction in access to the costly secondary care services that underpin the cost-effectiveness model developed by Frontier economics.

Indeed, any financial savings would be likely to be realised over a significantly longer timeframe than this pilot, and are perhaps more likely to be realised in primary, community or social care. If they do surface, they are unlikely to be directly linked back to a historic cancer diagnosis. It may therefore be useful for the next stage of the pilot and any evaluation work to focus on capturing and quantifying any reduction in the use of primary, community and social care services that result from an intervention delivered by a One-to-One Support team.

The findings to date suggest that the one-to-one support model is unlikely to generate savings in the short-term (with the exception of support workers who are working directly with CNS and are therefore improving efficiency of specialist staff), but is an effective means of meeting previously unidentified need, improving patient experience and quality of life, and potentially addressing many of the concerns raised by people affected by cancer in the national cancer patient experience survey.

Appendix 1: Postholder Data Collection Tool

An example of a blank data entry form is shown below.

Example postholder data collection form

The data form is split into the following sections:

- **postholder details:**
  Shows information regarding:
  - postholder's name
  - time period for which the postholder is submitting
  - site
  - role
  - pay band
  - whole time equivalent (WTE)

- **days worked/ lost:**
  Shows how the number of hours employed for is allocated to:
  - working time
  - time taken as annual leave
  - sickness absence
  - Continuing Professional Development (CPD)

- **split of time:**
  Shows how the number of hours worked is allocated to:
  - direct patient care – time actually spent with patients in a group or one-to-one support context, either face to face or over the telephone
  - patient administration – administration that is directly connected to the care of a patient, but without the patient present, for example managing the patient record, inputting data about a contact on the system
  - care coordination – including consulting with colleagues/other professionals
  - receiving training/CPD
  - providing training/CPD
  - patient education – including delivering workshops or developing materials
  - internal team meetings
  - working with external stakeholders
  - travel – any travel carried out during the working day, excluding your travel to and from work
  - collecting/inputting evaluation data – including completing the data spreadsheet, coordinating the patient survey for the evaluation, etc.
  - general administration – for example timesheets, expenses, and any other activity not categorised above

- **group contacts:**
  Shows the number, average length and types of group contacts made during the time period

- **individual contact types and outcomes:**
  Shows for One-to-One Support contacts:
  - how many contacts were made alone or with another health care professional (HCP) present

- location of the contact:
- hospital (inpatient, outpatient), GP surgery, hospice, community, home, telephone, other
- how many contacts were new or follow-up
- outcome of the contact/ how many contacts required:
- holistic needs assessment, assessment and care planning, providing education, advice, support etc., supporting self-management, routine follow-up, referral to other service, test ordered, leading to discharge, leading to avoided hospital admission, other outcome

- **individual contact need:**
  Shows for One-to-One Support contacts:
  - severity of cancer:
  - level 1 (least severe), level 2, level 3 (most severe)
  - location of cancer:
  - breast, lung, colorectal, prostate, other

- **individual contact demographics:**
  Shows for One-to-One Support contacts:
  - gender split
  - age category:
  - <40, 40–49, 50–59, 60–69, 70–79, >79.
  - ethnicity:
  - white British, white Irish, any other white background, white and black Caribbean, white and black African, white and Asian, any other mixed background, Indian, Pakistani, Bangladeshi, any other Asian background, Caribbean, African, any other black background, Chinese, any other ethnic group, ethnicity not stated or not available

Appendix 2: Data Cleaning (Postholder)

Preliminary data cleaning was performed on the postholder data to ensure it was in the correct format and valid. The following processes were performed:

Days Worked/ Lost:
- some postholders had recorded "Total Time Employed" as the sum of "Total Time Worked", "Annual Leave Taken" and "Sickness Absence"; but did not include "CPD". Therefore, if this was the case, the value given for "CPD" was subtracted from "Total Time Worked"
  - This was performed with errors bounds of ±5%
- some postholders had recorded "Total Time Employed" as equal to "Total Time Worked". Therefore, if this was the case, the value given for "Total Time Worked" became "Total Time Employed" – ("Annual Leave Taken" + "Sickness Absence" + "CPD")
  - if, after these attempts at cleaning, the data still didn't sum correctly; the entry was removed from consideration

Split of Time:
- some postholders' sum of their split of time was not equal to 100%. Therefore, if this was the case (and their sum was between 95% and 105%), their split of time was scaled to sum to 100%
- if, after these attempts at cleaning, the data still didn't sum correctly; the entry was removed from consideration

Individual Contact Types and Outcomes:
- some postholders total number of individual contacts changed throughout the input form, therefore, all raw figures were expressed as percentages e.g. if the total number of patients seen was 19, the number of patients seen alone was 8 and the number of patients seen with another HCP present was 12; these were given as 19, 40% and 60% respectively
- following this, postholders were allowed to select more than one outcome for each patient contact. However, in some cases, this number exceeded the total number of patient contacts given earlier in the form. Therefore, if this was the case, the number of patients who had the outcome was set to the total number of individual patient contacts. E.g., if there were 50 patients in total, and 52 received a holistic needs assessment, this was changed to 50 patients

Individual Contact Need:
- some postholders' total number of individual contacts changed throughout the input form, therefore, all raw figures were expressed as percentages as in Individual Contact Types and Outcomes

Individual Contact Demographics:
- some postholders' total number of individual contacts changed throughout the input form, therefore, all raw figures were expressed as percentages as in Individual Contact Types and Outcomes and Individual Contact Need
- if the section regarding ethnicity was left blank, it was given that 100% of patients had "Unstated or Unavailable" ethnicity

Appendix 3: Pathway Data Collection Template

An example of a blank data entry form is shown below.

Example Pathway Data Collection Form

The data form is split into the following sections:

- **Coverage/ Site Details:**
  Shows information regarding:
  - the total number of patients diagnosed
  - the total number of patients with a designated One-to-One Support worker

- **Outpatients:**
  - number of patients referred to a hospital consultant with suspected cancer
  - number of new outpatient attendances (including procedures)
  - number of follow-up outpatient attendances
  - percentage of outpatient appointments (new and follow-up) for which the patient did not attend

- percentage of outpatient appointments (new and follow-up) cancelled by the patient
- percentage of outpatient appointments (new and follow-up) cancelled by the service
- average number of consultant led outpatient clinics per week for cancer
- average length of consultant led clinic (in hours)
- average number of appointments per consultant led clinic
- average number of nurse led outpatient clinics per week for cancer
- average length of nurse led clinic (in hours)
- average number of appointments per nurse led clinic

- **Inpatients:**
  - number of elective admissions to hospital for cancer (spells)
  - number of non-elective admissions to hospital for cancer (spells)
  - average length of stay in hospital for elective cancer spells
  - average length of stay in hospital for non-elective cancer spells
  - excess bed days for elective cancer spells
  - excess bed days for non-elective cancer spells
  - average tariff received per cancer spell
  - number of emergency readmissions to hospital within 28 days for cancer

- **Primary Care (PC):**
  - total registered population of practice(s)
  - total number of patients on the Cancer Register
  - number of patients with a designated Macmillan One-to-One Support worker during the specified period
  - number of primary care team contacts with patients in the cohort during the period, by location:
  - surgery, home visit, telephone contact
  - % of cancer reviews completed for applicable patients within the last year

- **Community Care (CC):**
  - number of patients with a cancer diagnosis on the community services caseload
  - number of patients seen with cancer as a primary need
  - number of patients seen with cancer as a secondary need

- **End of Life Care (EOL):**
  - percentage of cancer patients who died during the period and were on the Liverpool Care Pathway
  - percentage of cancer patients who died during the period who died in their place of choice

As a professional, you know cancer doesn't just affect the people you support physically. It can affect everything – their relationships, finances, work. You may feel that there aren't enough hours in the day to spend as long as you'd like with them or to answer all their questions.

Macmillan can help, whether it's offering additional benefits advice, guidance on returning to work, or helping people make plans for their future. We can help you give them the support they need to feel more in control of their lives.

Visit **macmillan.org.uk/professionals** to find out more.

And let your patients know they can contact us free on **0808 808 00 00** (Monday to Friday, 8am–9pm) if they need additional support.

For more information about the One-to-One support programme, contact: **jgoodchild@macmillan.org.uk**

**WE ARE MACMILLAN.
CANCER SUPPORT**