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Evaluation of the Macmillan Cancer Care Co-ordinator and Community Cancer Care Sisters work-stream for the South Tees Integrated Cancer Care programme (Macmillan South Tees Evaluation)

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This report presents the findings of an independent evaluation of the Macmillan Cancer Care Co-ordinator work stream and Community Cancer Care Sisters role for the South Tees Integrated Cancer Care programme. It has been prepared by The University of Sheffield, under contract to Macmillan Cancer Support. The findings and interpretations in this report are those of the authors and do not necessarily represent the views of the services or organisations involved in the delivery of the programme.

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Audience for the report

There are multiple target audiences for the evaluation of these Macmillan roles:

- Key members of Macmillan Cancer Support and its associated partners
- South Tees NHS FT Chief Executive, Non-Executive Directors and Executive Director for Cancer Services
- The Macmillan ICC Programme Board members and organisations including CCG’s, Local Government, the Northern Cancer Alliance, secondary care colleagues, commissioners and local third sector organisations.
- Local, regional and national project teams focusing on workforce and role development and service improvement in Cancer Care.
- A lay summary has been prepared for service users and carers/family members.

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Glossary

A&E	Accident and Emergency
AHP	Allied Health Professional
AOS	Acute Oncology Services
Community Sister	Community Cancer Care Sister
CCC	Cancer Care Coordinator
CCG	Care Commissioning Group
CNS	Cancer Nurse Specialist
CT Scan	Computerised Tomography Scan
DNA	Did Not Attend
FT	Foundation Trust
GP	General Practitioner
HNA	Holistic Needs Assessment
ITT	Invitation to Tender
ICC	Integration of Cancer Care programme
IM	Intervention Matrix
ITS	Interrupted Time Series
JCUH	James Cook University Hospital
LOS	Length of Stay
Macmillan	Macmillan Cancer Support
MAU	Medical Assessment Unit
MacICC	Macmillan Integration of Cancer Care programme (The Programme)
MDT	Multi Disciplinary Team (meetings)
MI	Motivational Interviewing
MRI Scan	Magnetic Ressonance Imaging Scan
NICE	National Institute of Care and Health Excellence
NHS	National Health Service
PABC	Person Affected by Cancer
PET Scan	Positron Emission Tomography Scan
ROI	Return on Investment
SROI	Social Return on Investment
SPC	Statistical Process Control
UGI	Upper Gastro Intestinal
Work-packages	The division of the evaluation into qualitative and quantitative activities
Workstream	The focus of the evaluation; i.e. implementation of the two new roles (CCC & Community Sister)

Executive Summary

Background

The Macmillan Integration of Cancer Care programme (MacICC) was established in February 2014 as a partnership programme between Macmillan Cancer Support and South Tees NHS Foundation Trust and is scheduled to finish in December 2018. Following completion of an earlier review and consultation process, additional funding was secured to support implementation of the recommendations made by the review. Simplified care pathways, streamlined referral processes and care closer to home were identified as key ways of helping patients. This evaluation is focused on the two new roles that were developed and implemented as a result of the review, as described below.

Macmillan Cancer Care Coordinator (CCC) role

The CCC roles are designed to fill the gap between the health care assistant and a qualified nurse. The aim of the role is to provide effective, caring and compassionate services to patients working within a multi-disciplinary team (MDT) in a hospital setting. This involves co-ordinating care from referral to the end of treatment and requires regular contact with patients. It had been recognised that the wide-range of tasks being performed by qualified clinical staff members were limiting the effective use of their skills and experience.

The role involves liaison with other colleagues and departments in the hospital, signposts patients and ensures effective progress along their care pathway. The role in conjunction with the Cancer Nurse Specialists (CNS) and Allied Health Professionals (AHPs) is intended to provide coordination of high quality patient care through on-going identification of needs.

Community Cancer Care Sisters (Macmillan) role

The new Community Cancer Care Sister (Macmillan) roles (hereafter referred to as Community Sisters) are designed to work across traditional boundaries to help support improved working relationships with community health and social care colleagues including District Nurses, Community Matrons, GPs and Social Workers, improve skills and knowledge and skill sharing between specialists and specialist generalists, prevent silo working and support skill matching with other specialist nurses such as Community Macmillan Nurses. The Community Sisters are intended to provide holistic, coordinated community care, information and support based on the needs of service-users and their families.

Evaluation approach

Work-package 1, Qualitative: The evaluation was guided by the first work-package, which used a Realist Evaluation approach, starting by building a logic model which describes how the intervention is intended to work and the assumptions that need to be fulfilled to obtain optimum benefits. We used this as a framework to begin to uncover what works, for whom, in what circumstances and why. We used a combination of methods including interviews and group discussions with Macmillan staff, colleagues, service-users and other key stakeholders. We also used routinely collected data (such as descriptions of interventions from the Intervention Matrix) to help develop theories to explain outcome patterns. This approach is intended to not only describe what has happened from the perspective of various key stakeholders, but also provide refined and tested theories about why the intervention might work.

Work-package 2, Quantitative: A second work-package was focused on an assessment and analysis of routinely collected data. We investigated; overall time saved on the 62-day pathway, changes to A&E service use, changes to non-attendance at appointments, time saved for other professional groups. Additionally, we investigated time and cost savings on patient travel. We also calculated the return on investment for the programme.

The quantitative work relied on routinely collected, hospital-level data and data collected by post holders of the roles being evaluated. These data were collected in a spreadsheet called the Intervention Matrix (IM), and recorded activities and areas of cost savings; for instance, time saved for others, and prevention of missed appointments.

Findings

Work-package 1, Qualitative

The qualitative findings have been organised into the following 10 main topics:

- Topic 1: Understanding and implementation of the CCC role
- Topic 2: CCC Connection with other services
- Topic 3: CCC Impact
- Topic 4: Sustainability of the CCC roles
- Topic 5: Understanding of the Community Sister role
- Topic 6: Community Sister connection with other services
- Topic 7: Community Sister impact
- Topic 8: Implementation of the Community Sister roles
- Topic 9: Sustainability of the Community Sister roles
- Topic 10: Patient Experiences of Community Sister Roles

Some key findings are that the post-holders for the CCC and Community Sisters roles were highly motivated. They see the roles as intrinsically valuable and view the Macmillan training, support and experience to be particularly valuable. The CCCs and Community Sisters were able to provide holistic services. Specifically, they view the roles as filling a gap in current services and appreciate the quality that they can provide regarding improved patient experiences and improving the efficiency of surrounding health care systems. The improvement in patient experiences was supported by routinely collected data and discussions with staff and service-users.

The role-boundaries for CCCs and Community Sisters underwent an initial period of rapid development and definition, but continue to evolve. Whereas the CCC role boundaries seem to develop fairly naturally, depending on areas of greatest need within specific cancer specialties, the Community Sisters had to be more pro-active in the definition and evolution of their role. Fortunately, the roles tend to fit into well-defined gaps in services. However, there are some areas of overlap and whilst some service providers are keen to pass over responsibilities, others are more protective of their responsibilities, and this tension requires careful management and local tailoring.

The Macmillan branding of the roles has pros and cons. Whilst the alignment with Macmillan is a motivating factor for staff, owing to the support and training opportunities, the public perception of Macmillan is associated with end of life care. This created barriers to engagement with patients.

The knowledge of the CCCs regarding available services and cancer care pathways was both as a result of prior experience and initial induction and training for the role. This knowledge was crucial for the key mechanisms of the role to function. For instance, being able to make a rational case for speedy investigations or treatments to align with necessary decision points and other elements of the pathway helped for patients to have a more efficient treatment journey.

Discussions with service-users about the Community Sister roles confirmed that, from their perspective, the roles filled a clear gap in service provision. They felt able to discuss broad topics, developed strong relationships and valued the holistic, family-focused approach. Outcomes included being able to socially and emotionally deal with the illness and to resume a more normal life of activities. Some specific activities, such as making treatment recommendations, helping to make difficult decisions and intervening to solve problems with other services were reported to be particularly important. Service-users were unhappy about the limited availability of Community Sisters and reported having to overcome misconceptions about Macmillan services being for end of life only, prior to accepting the service.

Members of staff from both roles were required to complete an information database called the Intervention Matrix (IM), which quantified their activities and sought to measure the savings that their roles were making for the health care system. The completion of the IM was considered to be a burden. Whilst the CCCs reported being aware of the value of completing the IM, owing to receiving feedback about the extent of the economic value of their role, the Community Sisters reported that they were aware of the IM outputs being used at a senior level, they had not received feedback about the value of this information and felt that it did not truly reflect the work that they carried out.

Work-package 2, Quantitative

It is estimated that the salary costs for all staff members required to develop, implement and deliver the service over the 21-months between October 2016 & June 2018 was £550,509.05. These costs include programme management and administration (£37,338.80), which would not be required once the delivery model is embedded as business as usual. The costs for only the CCCs (x7[1]) and Community Sisters (x3) that would be required to deliver the service on an ongoing basis (post implementation) would be £513,170.25 for 21 months (£293,240.14 per year). Please see the full report for included and excluded costs and assumptions.

The IM included information about the time saved for other members of the health care workforce by activities of the CCCs and the Community Sisters, with descriptions about how the saving was brought about. The total saving for both roles is estimated as £184,237.57.

In England, the 31-day target refers to the target for the maximum time from receiving diagnosis to first definitive treatment. The 62-day pathway in England is defined as beginning first definitive treatment

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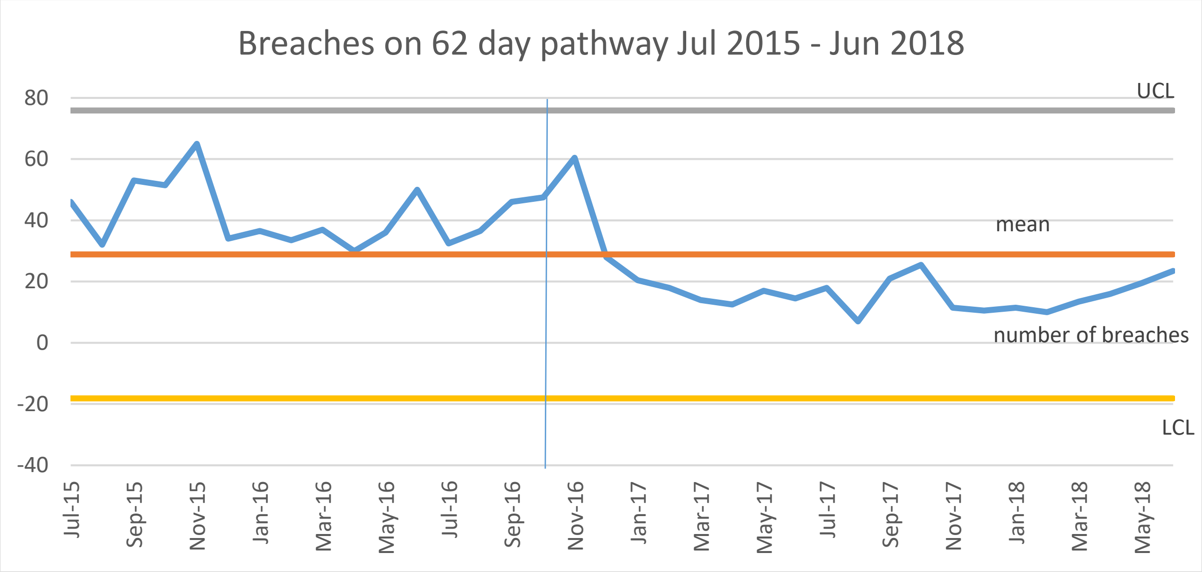
[1] While Macmillan funded six Cancer Care Coordinator post, for this evaluation, we also included in our analysis a previously substantive post which was transitioned into this new role.

following urgent GP referral. This can be used as a measure of patient experience, but it also carries financial penalties for Trusts if they fail to achieve 85% compliance with the 62 day pathway. The number of breaches was observed to decline following the intervention and subsequently compliance increased. By way of example, the following chart shows breaches on the 62-day pathway for colorectal, lymphoma, head neck, lung and prostate cancer patients between July 2015 and June 2018. The intervention was in October 2016. This shows a special cause variation indicating a trend due to assignable causes. We observed a reduction in people waiting over 62 days from above the average of 30 breaches per month before the roles were introduced, to being consistently below the average from 3 months after the roles were introduced.



The prevention of non-attendance at consultations (did not attend (DNAs)) was also recorded in the IM. The overall estimated cost saving was £9,591 between January 2017 and June 2018. If these savings are assumed to extend across the entire intervention period this would equate to ((£9,591/18)*21) £11,189.50.

Changes in A&E attendances for cancer patients were gathered from hospital records and analysed using Interrupted Time Series Analysis. Using monthly A&E attendance data for all patients with a primary cancer diagnosis, effects were calculated for 6-months, 12-months and 21-months post-intervention. Before the intervention there was a trend in the slope of an increase of 9.512 attendances every month, which became a negative post-intervention trend of -0.649 (p=0.001). This finding indicates that prior to the intervention there was a month-on-month increase in A&E attendances for all cancer patients. After the implementation of the new roles there was a slight, yet statistically significant month-on-month reduction in attendances. The overall difference between the pre-intervention trend and the post-intervention trend is -10.161 cases per month.

The following findings show an estimate of the difference between the actual A&E data and the forecast of the number of attendances that would have been expected to occur without the intervention at different time periods post-intervention.

- Six month level effect is a decrease of 93.311 cases per month (p=0.01; 95% CI=-24.4387 to -162.183)
- Twelve month level effect is a decrease of 154.276 cases per month (p=0.002; 95% CI=-60.489 to -248.063)
- Twenty-one month level effect is a decrease of 245.721 cases per month (p=0.001; 95% CI=-108.335 to -383.107)

To calculate cost savings to the acute care system, a slope equating to a reduction of 245.721 cases at 21 months and 0 reduced cases at the intervention point was applied. Assuming a cost of £148 per A&E attendance (Reference Cost Data 2016/17) this equates to a saving of £381,850.43 ((245.721*21)/2) over the evaluation period. Assuming that this difference continues for the following 12-months this could equate to a potential saving of £ 436,400.50 per year.

Return on Investment

The calculated costs and economic benefits assumed to be associated with the implementation of the roles are shown in the following table. Please see the full report for assumptions and limitations regarding these calculations. It should also be recognised that we have good evidence to support the assumption that the intervention was a key reason for changes in A&E attendances and subsequent savings, as the quantitative findings are supported by qualitative investigation, intervention matrix (IM) records and the testing and refinement of programme theories. For instance, the following extract from the IM record indicates a direct relationship, demonstrating how the CCC role can free up time for CNSs to deal appropriately with emergency situations, rather than patients resorting to A&E attendances.

> *Attended clinic with Consultant. Freeing time up for CNS to organise emergency admission/treatment for another patient*

The CCCs frequently carry out activities that enhance patients' practical abilities to self-manage they are also active in case-findings and ensuring that patients are not lost in the system and avoid delays in their care. A large number of contacts between CCCs and patients and their family members involve psychosocial support, information-giving and signposting to other services to improve abilities to self-manage health conditions.

The following extract demonstrates the well-established relationship between patients being supported to better manage their health conditions and less reliance on emergency services.

> "We found that patients who were most able to manage their health conditions had 38% fewer emergency admissions than the patients who were least able to. They also had 32% fewer attendances at A&E, were 32% less likely to attend A&E with a minor condition that could be better treated elsewhere"
>
> (Deeny et al, 2018)

However, whilst we have taken all available steps to explore other possible reasons for these observations, alternative explanations cannot be ruled out. The sensitivity analysis shown in the following table should therefore be useful if decisions are subsequently made to disregard any of the areas of savings.

Sensitivity analysis for ROI, at 21-months post-intervention

	Costs		Savings				Return on Investment	
	Cost of roles	Implementation staff	Other staff time-savings	A&E Savings	DNA savings	Patient travel	ROI Ratio	ROI £
A	£513,170.25	£37,338.80	£184,237.57				0.33	-£366,271.48
B	£513,170.25	£37,338.80	£184,237.57		£11,189.50		0.35	-£355,081.98
C	£513,170.25		£184,237.57				0.36	-£328,932.68
D	£513,170.25		£184,237.57		£11,189.50		0.38	-£317,743.18
E	£513,170.25	£37,338.80	£184,237.57	£381,850.43			1.03	£15,578.95
F	£513,170.25	£37,338.80	£184,237.57	£381,850.43	£11,189.50		1.05	£26,768.45
G	£513,170.25		£184,237.57	£381,850.43			1.10	£52,917.75
H	£513,170.25		£184,237.57	£381,850.43	£11,189.50		1.12	£64,107.25
I	£513,170.25	£37,338.80	£184,237.57	£381,850.43	£11,189.50	£47,133.3	1.13	£73,901.78
J	£513,170.25		£184,237.57	£381,850.43	£11,189.50	£47,133.33	1.22	£111,240.58

Using the costs and savings from row F in the table above (i.e. full staff costs for development, implementation and delivery and savings for the healthcare system), the programme provides a £1.05 return for each £1.00 invested over 21 months (£26,768.45). According to these calculations the break-even point (£2,346.64 return) for the South Tees pilot programme occurs in month-13 after implementation (November 2017). If the development and implementation costs are not included (i.e. costs of service-delivery roles only), then the programme workstream has far exceeded the break-even point at 21-months, with a return of £1.12 for every £1.00 invested (£64,107.25).

Non-elective admissions: Whilst not able to explore admissions data, we could assume that the national rates for conversion of an A&E attendance to emergency admissions apply. According to 2017-2018 national data, the average conversion rate is 28.655% of all A&E attendances at major A&E departments resulting in an admission. This would equate to a potential reduction of 844.94 emergency admissions per year (28.655% of 2948.65 cases). Assuming the national average non-elective inpatient cost of £1,590 (Reference Cost Data 2016/17) this represents a possible additional saving of approximately £1.3M/year (£1,343,454.60).

Conclusions

As the running costs (staff salaries only) are exceeded by the month-on-month returns on investment, and the programme is in a steady-state, it is reasonable to assume that appropriate increased capacity (i.e. providing adequate Community Sisters for the geographical area and expanding CCC roles to all cancer sites) will result in incremental cost savings for the health-care system. Future programmes will also expect a break-even point that is sooner than demonstrated in this pilot programme. The non-financially quantified improvements in quality of care and patient/family experience will also be expected to increase as the roles saturate the system and become better integrated.

The roles were highly valued by the colleagues, service-users and family member consulted. There are clear and justifiable theories for how the roles create improved experiences for people affected by cancer and their families, and how the work experience of other health care professionals is improved. There are notable gaps in service provision that the roles fulfil. There is evidence that the holistic and flexible approaches of the Community Sisters allows people affected by cancer (PABC) and their families to quickly become more resilient, resume a sense of normality and receive advice and support for navigating services.

The Coordinator roles allow clinically trained members of staff to focus on levels of tasks that are more suitable to their experience and training, and improve the speed of services and user experiences. The roles have proved to be innovative, as previous roles linked to poorly coordinated health service processes rather than developing relationships with patients and coordinating service from the perspective of patient experiences. They are continuing to evolve and as such provide a platform for further improvements in cancer care pathways, potential efficiency savings and enhanced experiences of PABC.

It should be recognised that this was a rapid evaluation, and there were limitations in both the quality and type of information available, and therefore the conclusions that can be drawn also have limitations and rely on certain assumptions that needed to be made. Whilst we believe that the evaluation presents a strong case for the benefits of these roles for a wide range of people and services, they would benefit from more in-depth investigation, particularly if there are plans to scale up the programme.

Lay Summary

Background to the programme

The Macmillan Integration of Cancer Care programme (MacICC) was established in February 2014 as a partnership programme between Macmillan Cancer Support and South Tees NHS Foundation Trust and is scheduled to finish in December 2018. This evaluation is focused on the two new roles that were developed and implemented as a result of the programme; the Cancer Care Coordinator (CCC) and the Community Cancer Care Sisters (Community Sisters).

Macmillan Cancer Care Coordinator (CCC) role

The CCC roles are designed to fill the gap between the health care assistant and a qualified nurse and are based in services that are focused on certain cancer specialties (such as Lung Cancer or Colorectal). They work to support Cancer Nurse Specialists, Consultants and Allied Health Professionals (AHPs), such as Occupational Therapists, Speech Therapists and Physiotherapists. They provide a single point of contact with patients through diagnostics and treatment so clinical staff can concentrate on their areas of expertise. They also help to improve patient experiences by making sure that all their needs are assessed and by joining up services so that they receive the right treatment at the right time from the right person.

Community Cancer Care Sisters (Macmillan) role

The Community Sisters fill a gap in community services by providing care based on a wide range of patient's needs (including physical, emotional, practical, financial and spiritual concerns) from the point at which patients are diagnosed; whereas current community services are focused on clinical tasks or end-of-life care. They form a link for patients between hospital and community services, can help to solve problems, provide advice and support, explain treatments and investigations and help with difficult decisions.

Evaluation Approach

The evaluation was formed from two main approaches:

Firstly, we used interviews and group discussions and read available literature to describe the experiences and opinions of staff and patients and to understand what sort of benefits the roles might bring about and why.

Secondly, we gathered data about areas of the services that we expected to change as a result of the roles being introduced. For instance, we looked at the amount of Accident and Emergency services being used by people with cancer diagnoses, we looked at the amount of time that might be saved for other members of staff and reductions in missed appointments.

Findings

One of the key findings was that the roles were highly valued by the people in the roles, their colleagues and patients. They clearly filled gaps in services. Although we did not manage to speak to patients about the CCC roles, there was very good evidence about how the roles had improved patient experiences; for instance, by reducing waiting times, providing somebody to talk to that had time to deal with their concerns and increasing the extent to which all patients' needs were assessed.

Discussions with service-users about the Community Sisters confirmed that they felt able to discuss broad topics and develop strong relationships with them. They valued the approach to the whole person rather than immediate clinical needs and the family-focused approach. Outcomes included being able to cope better with the illness and to return to a more normal life of activities. Some specific activities, such as making treatment recommendations, helping to make difficult decisions and intervening to solve problems with other services were reported to be particularly important.

The Macmillan branding of the roles has pros and cons. Whilst the alignment with Macmillan is a motivating factor for staff, owing to the support and training opportunities, the public perception of Macmillan is associated with end of life care. This created barriers to engagement with patients.

We explored standards in the times that patients are expected to wait for services. The 62-day pathway in England is defined as beginning first definitive treatment following urgent GP referral. This can be used as a measure of patient experience, but can also carry financial penalties for Trusts if they do not achieve a 62 day pathway. Over the period we collected data for (July 2015-June 2018) the average number of people waiting over 62 days was 30 per month. Before the roles were introduced there were more than 30 people every month waiting longer than 62 days. We observed a reduction, so that the number of long waits was consistently below the average from 3 months after the roles were introduced, and at one point dropping below 10 people per month.

We also produced a forecast of the numbers of attendances at Accident and Emergency (A&E) for people with a cancer diagnosis, which showed a month-on-month increase prior to the introduction of the new roles. However, after the roles were introduced there was a slight reduction every month. We could not find any other reasons for this effect other than the new roles. This suggested that at 21-months after the new roles, there had been a reduction of about 245 attendances to A&E per month, which could be equal to a saving of about £381,850 over the course of the 21 month observation period.

We conducted a Return on Investment Analysis. If we consider the costs of providing the new roles over 21 months (investment of £550,509.05) and compare this to the potential savings (returns) from reduced A&E attendances (£381,850), reduced missed appointments (£11,189) and savings from the time of other members of staff (£184,237), the programme provides a £1.05 return for each £1.00 invested (£26,768.45). We also calculated that the programme broke even after 13-months, regarding the balance of investment to returns.

Conclusions and recommendations

The new roles are widely regarded as valuable both in terms of health service efficiency and patient experience. We found good quality evidence to support the claim that the new roles helped to provide the right care, at the right time, with the right person. The evidence that we gathered from talking to people and understanding how the programme might work was supported by the examination of the other available data.

The findings support the further adoption and spread of the CCC roles to other cancer specialties and the expansion of the Community Sister roles so that more people, particularly those in more remote areas can benefit. The economic evaluation indicates that this should result in further savings across the health care system to offset any additional costs in providing the service. There is also potential for the roles to take on additional responsibilities to further improve pathways for cancer care and support.

It should be recognised that this was a rapid evaluation, and there were limitations in both the quality and type of information available, and therefore the conclusions that can be drawn also have limitations and rely on certain assumptions that needed to be made. Whilst we believe that the evaluation presents a strong case for the benefits of these roles for a wide range of people and services, they would benefit from more in-depth investigation, particularly if there are plans to scale up the programme workstream.

MAIN REPORT

Programme background

The strategic aim of the programme is to integrate cancer care by promoting patient choice and streamlining working practice across the South Tees and Hambleton, Richmondshire & Whitby health economy; looking at how all the separate services can work more closely to deliver the right care, in the right place, at the right time, by the right professional.

Background context to the Macmillan Integration of Cancer Care programme

The Macmillan Integration of Cancer Care programme (MacICC) was established in February 2014 as a partnership programme between Macmillan Cancer Support and South Tees NHS Foundation Trust, phase 2 of which finished in December 2018. The MacICC Programme was extablished with eight agreed workstreams. Phase 1 identified that simplified care pathways, streamlined referral processes and care closer to home was needed. Additional funding was secured to support implementations of the recommendations; thus the addition of the two roles evaluated in this report. The implementation of these two new roles as described below will be referred to as the workstream, for the purposes of this report.

Partnership approach

The responsibility for the commissioning and provision of cancer care services lies with a number of different organisations across the local health economy. Efforts have been made to establish a partnership approach to ensure that patient care remains at the heart of service delivery.

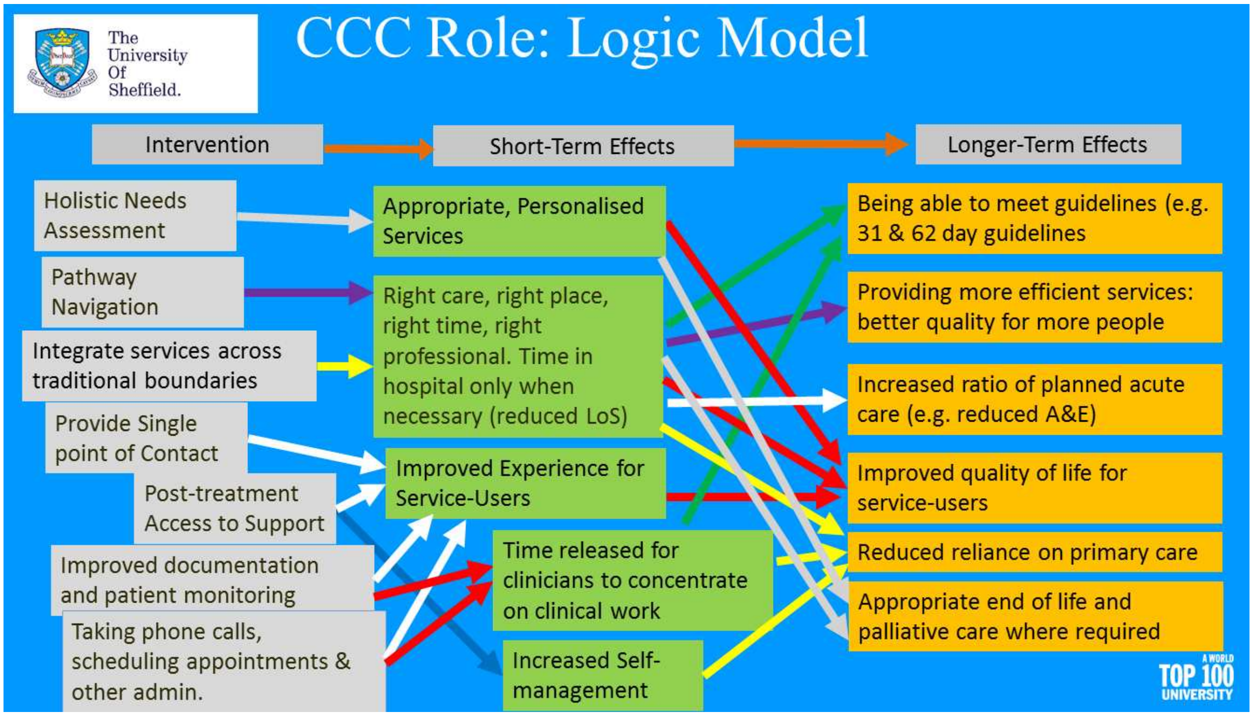
The MacICC Programme Board has secured engagment and representation from the following key partner organisations: Macmillan Cancer Support, patient representative board members, Local Authorities, Public Health, Voluntary Development Agencies, Teesside Hospice, Haematology, Macmillan Lead Cancer Nurse, Macmillan GPs, CCGs, Director of Nursing, Middlesbrough & Stockton MIND, as well as the South Tees Strategic Lead for Cancer. The following visual logic models (Figure 1 & Figure 2) demonstrate some of the theoretical constructs underlying anticipated outcomes of the roles.

Background context to the Macmillan Cancer Care Coordinator (CCC) role

The CCC roles are designed to fill the gap between the health care assistant and a qualified nurse. The aim of the role is to provide effective, caring and compassionate services to patients working within a multi-disciplinary team (MDT) in a hospital setting to deliver a high standard of care and support to patients with cancer. This involves co-ordinating care from referral to the end of treatment and requires regular contact with patients. The introduction of the CCC roles were intended to fill gaps in services that had been identified around the coordination of care and effective communication with service-users. It had also been recognised that the wide-range of tasks being performed by qualified clinical staff members were limiting the effective use of their skills and experience.

The role involves liaison with other colleagues and departments in the hospital, signposts patients and ensures effective progress along their care pathway. The role in conjunction with the Cancer Nurse Specialists (CNS) and Allied Health Professionals (AHPs) is intended to provide coordination of high quality patient care through on-going identification of needs, including increasing opportunities for conducting Holistic Needs Assessments (HNAs). A HNA covers a range of possible concerns that a PABC might have, including physical, emotional, practical, financial and spiritual concerns, which helps in the development of a care plan. The following visual logic model (Figure 1) demonstrates some of the theoretical constructs underlying anticipated outcomes of the role.

Figure 1: CCC visual logic model



Background context to the Community Cancer Care Sisters (Macmillan) role

The new Community Cancer Care Sister (Macmillan) roles (hereafter referred to as Community Sisters) build upon good practice already established and are designed to work across traditional boundaries to help support improved working relationships with community health and social care colleagues including District Nurses, Community Matrons, GPs and Social Workers, improve skills and knowledge and skill sharing between specialists and generalists, prevent silo working and support skill matching with other specialist nurses such as Community Macmillan Nurses. The Community Sisters are intended to provide holistic, coordinated community care, information and support based on the needs of service-users and their families (see Figure 2).

Figure 2: Community Sisters visual logic model

Evaluation approaches/methods

Overall aims and objectives

The following table summarises the overall aims and objectives of the evaluation. Underlying the aims of the evaluation are the key questions identified in the Invitation to Tender (ITT) (see appendix 1).

Table 1: Overall evaluation plan

Main aim	Aims	Objectives
Assess the changes to service-delivery and the experiences for people affected by cancer that can be attributed to the implementation of Cancer Care Coordinator (CCC) and Community Cancer Care Sister (Community Sister) roles in	Capture insight from the Macmillan staff and colleagues on their views of the role and understand from their perspective the value and contribution to patients and to the Trust	Develop initial programme theory of change to understand the types of interventions, anticipated benefits and rationale for how they might bring about these benefits. This will be completed using a combination of documentary analysis and initial discussions.
	Capture and integrate additional insight from stakeholders on the value and contribution of the Macmillan CCC and Community Sisters roles with a specific focus on benefits to partners	Design an initial set of theory-led topics to be explored through qualitative investigation.
	Add to the body of learning on support worker roles, particularly Macmillan Cancer Care Coordinators and Community Sisters, their contribution to skill mix and improved outcomes	Refine and test the logic and assumptions of the intervention using qualitative interviews and group discussions.
	Determine whether these roles have supported better integration of	Identify the current and anticipated main users and uses of service-level metrics, and

South Tees	services from the perspectives of the healthcare system, staff and patients	explore whether the current metrics are providing the required information.
	Support the programme team to analyse the Intervention Matrix data and to create a narrative bringing available information together	Assess the suitability of the evidence provided by the current Intervention Matrix.
	Determine whether these roles have supported better streamlining of services from both a staff and patient perspective and improvement of patient experiences (from diagnosis through to palliative and end of life care)	Explore the ability to monitor the economic impact of the programme using current metrics, and suggest alternatives if appropriate

Methodology

The evaluation applied a theory-driven (Pawson and Tilley, 1997, Pawson 2013) mixed methods approach using a combination of qualitative methods and routinely collected quantitative data. This approach allowed us to examine the theories of change defined in the Integrated Cancer Care Programme logic and the new Macmillan CCC and Community Sisters roles. The rationale underpinning the programme and roles was refined and tested with key stakeholders through conducting face-to-face and telephone interviews and group discussions (e.g. focus groups). The evaluation was organised into two work packages (qualitative and quantitative) as detailed below:

Work-packages

Aims and objectives

The following table summarises the organisation of the evaluation into both qualitative and quantitative work-packages. Aims and objectives were achieved through the application of several approaches, via a series of phases of work.

Table 2: Evaluation framework

Work-package & Approach	**Aims**	**Objectives**	**Phase-one**	**Phase-two**	**Phase-three**
1. Qualitative • Logic models • Programme theories • Current evidence • Interviews • Focus groups	Explore the key evaluation questions through discussions with a range of stakeholders, to gain a variety of perspectives.	• Develop programme theories to identify whether the new roles work, and contexts that facilitate or inhibit the implementation • Examine whether the new roles improved patient experience • Explore cross-organisational working in order to elicit how the roles work in conjunction with existing roles such as CNS and AHPs	Develop the assumptions behind the CCC roles and Community Sisters roles	Examine professionals' perspectives of the CCC roles and Community Sisters roles	Understand the views of patients and family members **Phase-Four** Validation of initial findings with cancer care staff
Work-package & Approach	**Aims**	**Objectives**	**Phase-one**	**Phase-two**	**Phase-three**
2. Quantitative • Costing of the intervention in terms of staff and operating costs • Costing benefits achieved (e.g. staff time saved due to intervention) • Statistical process control charts • Content analysis • Interrupted time series	Use routinely collected data to assess the outcomes of the programme and the economic impact	• Examine the robustness of the evidence on time savings and resource use • Explore the usefulness and validity of the Intervention Matrix to determine the benefit and impact of the programme • Provide recommendations to develop the existing dashboard to support the analysis and understanding of the Intervention Matrix • Examine the Return on Investment (ROI) of the programme to identify whether they represent good value for money	Assess the robustness and the validity of the resource use and cost data associated with the CCC and Community Sisters roles	Assess the robustness and usability of the Intervention Matrix	Examine the Return on Investment (ROI) of the introduction of the roles

Description of work package 1: Qualitative evaluation

Phase 1: Developing the assumptions behind the Macmillan CCC and Community Sisters roles

We developed logic models to describe the context of the implementation, the components of the workstream, the process of delivery and implementation of the workstream, the predicted outcomes and the impacts of the programme. The theories and assumptions behind the programme were generated by conducting a rapid literature review and consulting key stakeholders. The logic model and underpinning assumptions were used to generate a series of hypotheses to inform and guide the evaluation. These hypotheses were then tested and refined with different stakeholders through interviews, focus groups and exploration of routinely collected data.

The theories developed in this phase were mainly focused on integrated and person-centred approaches to cancer care with stress on characteristics of integrated and cross-organisational partnership at different levels; including organisational, strategy, operational and delivery levels. The effect of the new integrated model on patient care and its impact on the relationship between individual multidisciplinary cancer teams and wider health system including CNS and other AHPs were explored.

Phase 2: Examining professionals' perspectives of the Macmillan CCC and Community Sister roles

Focus

The theories formulated in phase 1 were validated and assumptions tested in phase 2 using interviews (face-to-face and telephone interviews) and focus groups with stakeholders. We examined the stakeholders' understanding of the purpose and nature of the new roles and whether the new roles promoted an integrated and person-centred approach to cancer care. The barriers and facilitators to the development and implementation of the roles were examined within the larger context of implementation including their relationships with the other multidisciplinary cancer teams and what difference the roles made to the wider health system. We also explored benefits of the new roles in terms of quality, cost and time saved for other staff, their impact on the journey of a cancer patient, and to what extent the new roles meet the strategic direction of travel for cancer, and any plans to maintain the roles for future cancer care.

Participants

A purposeful sampling strategy was used to recruit a range of stakeholders who were involved in design, implementation and delivery of the new roles at a range of levels as well as those affected by the programme and the new roles in terms of team working and decision making. Fifteen individual telephone interviews were conducted with a range of staff and health professionals including the CCCs, CNSs (different site specific specialist nurses including Neuro-oncology, prostate cancer, UGI, and lung cancer), information centre staff, Palliative nurse specialists, and AHPs. A focus group was carried out with two Community Sisters. Another focus group was carried out with three CCCs and a one-to-one interview was conducted separately with one CCC who was not able to participate in the focus group.

Data collection

Interviews and focus groups explored the new roles and how they are perceived. The interviews also focused on understanding the impact of the new roles on work environment and the barriers and facilitators to the successful implementation. Interviews were conducted using an interview guide informed by the theories and assumptions generated in phase 1. Interviews were audio recorded and transcribed verbatim. A theoretical data collection approach was used in which the emerging themes from the interviews were explored further in follow-up interviews and focus groups.

Phase 3: Understanding the views of patients and family members

Focus

Towards the end of the evaluation, in phase 3 we examined patients and carers' perspectives about their experiences of the new roles. Participants' understanding of the nature and purpose of the new roles and the benefits of these roles was explored. The focus group was intended to explore patient and family members' experiences and opinions of the roles, and to primarily answer the following questions:

- All things considered would patients like to see these posts remain?
- Do patients understand the nature and purpose of these roles?

Participants

Three service-users attended a focus group session and one of the service-users was accompanied by her daughter. Unfortunately, the service-users only had experience of cancer services without CCC posts, and in the time available it was not possible to arrange further purposive recruitment. So the evaluation was not able to gain insight into patient experience with CCCs. However, participants had mixed experiences of the Community Sisters). One of the respondents (SU1) had been in contact with three Community Sisters, but they had shortly stopped visiting due to maternity leave and sickness. The other two service-users (SU2 & SU3) had experienced Community Sisters throughout their treatment and recovery, which provided a useful contrast and an insight into differences experienced by access to these services. SU3 was accompanied by her daughter (DoSU3).

Key themes covered during the discussion included; the types of support and topics of conversation provided by the Community Sisters, coverage of the service, service-users' needs, perceptions of the roles, relationships with the Community Sisters and outcomes as a consequence of receiving support. In the following quotes the name of the specific Community Sister is replaced by [CCCSis].

Data collection

The topic guide for the focus group with PABC was developed from the logic model and emerging programme theory. The session was audio recorded and transcribed verbatim.

Phase 4: Validation session

We also conducted a validation session with a wide range of cancer services staff members, including CCCs, Community Sisters and CNSs to explore their opinions about the preliminary findings, check facts and identify any areas of further exploration. The validation session with cancer services staff involved group exercises and the presentation of interim findings; with ongoing group discussion to confirm and refine findings, check facts and identify any areas of further exploration. Contemporaneous notes and outputs from the group exercises were collected and used to guide changes to the final stages of the evaluation (such as agreeing on service costs to include in the final report and how they should be described and incorporated).

Consideration of any ethical and other research governance issues

The protocol and associated documentation were reviewed by the University of Sheffield Research School of Health and Related Research (ScHARR) Ethics Review process. This involved consideration by two ethical reviewers, discussion at the ScHARR ethics committee and subsequent amendments to the process, documentation and protocol as requested. Informed consent procedures were used for the collection, use and storage of primary data. The evaluation was assessed as a service evaluation project, not requiring NHS ethics permissions and was registered with South Tees Hospitals NHS Foundation Trust.

Findings

Work package 1: Qualitative evaluation findings

The following section summarises the findings from the interviews and focus groups. Additional supporting quotes are provided in appendix 4.

The findings have been organised into the following 10 main topics:

- Topic 1: Understanding and implementation of the CCC role
- Topic 2: CCC Connection with other services
- Topic 3: CCC Impact
- Topic 4: Sustainability of the CCC roles
- Topic 5: Understanding of the Community Sister role
- Topic 6: Community Sister connection with other services
- Topic 7: Community Sister impact
- Topic 8: Implementation of the Community Sister roles
- Topic 9: Sustainability of the Community Sister roles
- Topic 10: Patient Experiences of Community Sister Roles

Topic 1: Understanding and implementation of the CCC role

Overview

Participants discussed mainly how the CCC role had a positive impact on different aspects of cancer care in acute as well as in community setting, and how it has allowed CNSs to change the focus of their roles. The role was considered to be particularly attractive for a number of reasons, including access to Macmillan training and support and being holistic and patient-facing. The tasks and responsibilities involved in the CCC role are dependent on the characteristics of the team they are working with. Hence, each role is somewhat unique and is tailored to meet the needs and requirements of services for particular cancer sites. The roles continue to evolve in line with changing needs and development of individual competencies.

Findings in this section are organised into the following themes:

- Motivational factors
- Helping CNS
- Patient-focused
- A holistic approach
- Role boundaries
- Evolution and clarity of the CCC role
- Macmillan-branded role
- Patient perception of the role

Motivational factors

The CCCs were particularly motivated to work in cancer services, despite the roles being fixed-term posts. The prospect of having contact with patients and providing support was also a motivating factor. Being a Macmillan post with the associated training, professional development and support was also a factor that attracted the CCCs to the post.

> "I've got experience of already working in oncology…I think that's where my passion was and I've gone to mental health and I want to come back into cancer." (CCC focus group)

> "It was a big risk going from a permanent post to a fixed term for 12 months …. It was just the risk I wanted to take, so I got more patient contact … and cancer it's just something you just want to be helping with and supporting people and it was the best risk I've took." (CCC focus group)

> "… it did attract me that it was a Macmillan post, and because of the development that you can get in there, and its experience and what you can learn from that. If I was just working on the ward, I don't know if I would get that same…" (CCC focus group)

Helping CNS

The CCCs had a strong focus on the value of their role in alleviating pressure from the CNSs, to free them up for more advanced clinical duties

> "It's been just like a specialist nurse is a qualified person who shouldn't be nipping along to radiology to get a CT scan brought forward or you know, talking to someone because they're just lonely, I mean they do that but there's a lot of medical things that they have to do and that's sort of where we step in as well, isn't it?" (CCC focus group)

Patient-focused

The CCCs valued the continuity of care that they were able to provide, to prevent patients from having to repeat their stories and to create a 'connection with them'. This relationship continued after treatment had formally concluded.

> "…over the pathway of the patient that because it's always you that's around…they don't have to tell their whole story to everybody. That they have that bond with you and you learn about the family and stuff right the way through and once they've even … been discharged, they'll still contact you just for general things…you have that connection with them." (CCC focus group)

> "I've started a follow up now… so the specialist nurses don't need to do that now. So, I'll chase them up afterwards and just see how they're doing and if there's anything we could help them with. So, it's after really they've had the treatment, so that's all the way through." (CCC focus group)

The information gained through the development of a relationship with the patient was something that one respondent considered they could pass on to Community Sisters and palliative care services, to assist them in being more patient-focused.

> “I think we are of some benefit in a way we know this patient from start … When we're referring to Community Sisters…or to palliative care, we can give that little bit more… you tell them the diagnosis, but you can say, ‘Oh, you know he’s got a dog called Spot and he’s wife’s in a wheelchair?’ It’s just those little things that we’ve picked up, it's just a bit more of an insight… not just an NHS number… where you think it might be petty and not necessary, but to us it is. Especially when they’re sat in clinic and you say,’ How’s spot doing? Is he being a little terror?’ … it’s just that little bit extra touch, so they feel like they know them when they go and see them. So I think we’re a help.” (CCC focus group)

They also valued the assistance that they could provide in coordinating care and speeding up the patient’s investigations and treatments.

> “I think our role also helps to push the patient throughout the pathway more quickly because obviously we can track… I’ll go get the MRI, bring it forward, pop down and see the department’. They will say, ‘Yeah, bring them down and we’ll get them in straight away’ instead of that patient waiting two days or three days for their investigations. Not that it’s just about tracking the patient, it's about the care of the patient.” (CCC focus group)

A holistic approach

Holistic Needs Assessment (HNA), long-term follow-up and involvement in coordinating wellbeing interventions were seen as key aspects of the role.

> “The prostate patients are offered a holistic needs assessment at the time of diagnosis. That’s followed up after post-surgery or post-treatment with the specialist nurse. We also have our patients that are followed up for 10 years, so that's quite a long time. We have, like this morning we had the wellbeing programme with a prostate surgical patient which is a six-week programme run by our survivorship nurse. So, I’m quite involved in recruiting the patients and attending the sessions which has been running for three years and is extremely popular. So, all along the way they have the holistic need assessment.” (CCC focus group)

Rather than conducting formal HNAs in a single sitting, the CCCs used the various contact opportunities with patients to glean important information from the patient and add this to their records for assessment regarding the care plan by CNSs. Importantly, it was recognised that having these conversations with patients would elicit information that the CCC would not be qualified to deal with. It is therefore important to have clear boundaries regarding the limitations of responsibilities of the role.

> “Without realising sometimes, you are doing a holistic needs assessment of a patient on the phone… even though you not going through a checklist … we record it all on our hospital system... Then my CNS can see that conversation I’ve had. So, if he rings again she can look at like two days earlier I’ve had this conversation… she can see from that if anything sets alarm bells off or we know it’s above our level of our job role. We then obviously say we’ll come back to you and pass it over to the CNS to take it up.” (CCC focus group)

> “It’s like a continuous thing, the holistic needs…We don't do an official document. I wouldn’t go in and do a holistic, so it’s something that we do continuously.” (CCC focus group)

However, it was felt that it is difficult to assess the value of the role, owing to this holistic focus on quality of care.

> “Holistic needs covers a lot of things not just medical terms, obviously the emotional state, the financial state, you know, how they’re getting on with the family and the children. So, it does cover a lot.” (CCC focus group)

Role boundaries

As discussed above, establishing and maintaining the boundaries of the new roles was an important aspect of the development of the posts.

> “Because you’re not a secretary, you’re not a tracker, you’re not a nurse, you’re not a healthcare assistant and you know those boundaries that you don't do those jobs because that’s somebody else’s to do.” (CCC focus group)

However, it was assumed that patients did not have problems making the distinction between the CCC roles and the nursing staff.

> “So it's about knowing your restrictions and knowing where that's got to be the medical team that take over because we're not actually nurses… it’s quite simple for the patient to see we’re not nurses. We’re there to help them as a layperson really.” (CCC focus group)

It was also recognised that colleagues might take some time to gain trust in the new roles and to understand what activities the CCCs are able to perform. This was one of the ways in which the roles developed differently in each different setting. Particularly in the early stages of the role development it was important that the activities of the CCCs were monitored to maintain appropriate role boundaries.

> “This is a new post working with specialist people that have been in post as single practitioners since the onset, and I think sometimes it's very difficult for them to trust you to do the job basically. So, for me personally, I think it's gaining that trust from the people that you work with, that they are able to say, ‘Yeah, she will be able to do that, I’ll leave that so the cancer care coordinator can do that’, and trust you to do it, and that takes a little bit of time and also to be able to fit in with the team, you know. We are in teams with all different people so you've got to be able to fit in with them.” (CCC focus group)

> “Some of these CNSs have been on their own for so long, and it has been hard to invite someone into their space, but I think they do value your opinion and listen to what you have to say… But they do protect us as well to make sure we're not doing something that we shouldn’t be doing, which is a really good thing on their part just making sure we are not over stepping or doing someone else’s job.” (CCC focus group)

Participation in MDTs was a key mechanism through which the new roles were better understood and the CCCs became appropriately involved in the work of the service.

> “I think people do understand what we are about. Through the MDT, the role is understood through the MDT meeting.” (CCC focus group)

Evolution and clarity of the CCC role

The main challenges facing both roles are others' understanding of the role including health professionals and patients' perceptions of the roles. For the CCCs there has been a process of tailoring the role to each of their unique contexts, and the need to maintain the alignment of role expectations and competencies.

At least initially, the CCCs role was reported to be liable to be confused with administrator roles, MDT roles and nursing roles. The role benefits from clear management, to describe it in detail and inform colleagues about expectations of the role.

The roles had evolved over time (for instance taking responsibility for deadlines regarding transmission of information), and still had capacity to develop (e.g. in some clinical assessment tasks); demonstrating a potential for formal career development opportunities, which were not built into the roles from the outset. The CNS participants believed that the role involves a mix of responsibilities including running all the "back of house audits" such as collecting data, answering phone calls and responding to them, triaging the patients including looking into blood tests and collecting data for audits, ensuring audits are up to date, doing the admin work to free time for clinical work, tracking patients and ensuring they are on the correct pathway, and dealing with GPs and other health care professionals.

Macmillan-branded role

Whilst the CCCs saw that there were advantages with the association of the role with Macmillan cancer support, the Macmillan branding was reported to create barriers and concerns in dealing with patients, owing to the connection with end of life care. They found that they either tried to hide their badge or explain to the patients that they were not providing end of life care. This public perception problem was noted as a strong theme of the evaluation.

> "I think a lot of patients when they think of Macmillan think of 'end of life'." (CCC focus group)

> "So, it was scary at first when you were going into clinic. You used to have to hide your badge… they'd be like, 'Oh god, I haven't been told anything but they've already got a Macmillan person here and it freaked them out. So… you've got to judge all that." (CCC focus group)

> "I think when we started clinics … we made it a point to say we are Macmillan because Macmillan funded this … we try to make it clear it's not the 'end of life' part of Macmillan… So, that was another point to try to get across, why we've got the Macmillan badge." (CCC focus group)

Patient perception of the role

Regarding the perception of how the CCC role is received by patients; there was an assumption that they would not necessarily know the difference between the roles. However, one respondent stated that the roles of the CCCs are clearly understood by patients. This aspect of the patient understanding of the role would benefit from further investigation. It was assumed that patients would be happier if their call was answered by a person rather than an answering machine, which would often be the alternative. Generally the role was assumed to help the patients feel supported, satisfied and reassured, and to prevent frustrations due to communication and coordination problems.

Topic 2: CCC Connection with other services

Overview

The CCCs valued the initial period of training and induction, particularly the understanding of and relationships with a wide range of services. The CCCs have developed connections with AHPs through picking up work that they were having problems completing and introducing new deadlines for transferring assessment information. Being able to focus on personal relationships with other service providers facilitates a more rapid service provision. An understanding of cancer pathways (through experience and training) helps CCCs to negotiate with members of staff to advocate for improved services for patients. This section is organised into the following themes:

- Connection with AHPs
- Connection with the community
- Knowledge of available services
- Knowledge of the pathway including the negative impact of delays on patients

Connection with AHPs

The integration of the CCC roles with AHPs was assisted by picking up work that existing members of staff did not have time to complete. For instance CCCs have taken over maintaining databases and ensuring that deadlines are set and achieved.

> "I held a meeting last week with some of the allied health professionals because they've got a database of all of the patients that are pre- and post- surgery that they see… it was the physios that were logging all of that. They didn't have time, they're so busy and so I have taken over the database…. So, I held a meeting last week with the psychologists and the other allied health professionals because there were patients' notes that have sat there for months and they were results that hadn't been sent to the consultants. That is purely because they were just so bogged down… So now, part of my role is to keep on top of that database. So, I've asked last week if we can start to give deadlines when the results get given to the consultants… So we've got a week's turn over and now it's working." (CCC focus group)

Integration with AHPs has been assisted by conducting pre-and post-surgery discussions with patients and helping to manage aspects of ongoing support such as ordering equipment, particularly when AHPs are too busy to respond quickly. This is another way in which the CCCs help to provide a faster service to patients and support improvements in patient care.

> "I'm also involved in the inter-disciplinary team, so I'm linking with a psychologist, the occupational therapists, physio and speech and language therapist service. So, every Wednesday and Thursday we see patient's pre-surgery and post-surgery. Then we see how they are doing at home, if there's anything that we could help with. So, I have a lot to do with that aspect, because especially if your physio or OT's busy on the ward, they might say, 'Oh [x], could you go order them a wheelchair?', or 'can you just go do this for me, do that for me?' So, I think it does take a lot of workload off them as well." (CCC focus group)

Connection with the community

Connections between CCCs and community services were facilitated by going out to meet community service providers during their induction. It was also recognised that this relationship could help with the sustainability of these community services, so it was felt that they had a symbiotic relationship.

> "That was the whole thing why we did our induction at the start to get out there… Obviously discussing with our CNS as appropriate, but they have allowed us to make referrals to the holistic centre, social services, the exercise program in the council, and by going out there and meeting these people personally it's really helped ... We bring these community people in to talk to our patients to help promote it because a lot of them are funded and volunteer sector, so we help promote them so they can keep going as well." (CCC focus group)

Knowledge of available services

The CCCs discussed visits to other services, and awareness-raising about other services during their induction and training. The results of this were recognised in reports of CCCs regularly referring patients to a wide variety of services, such as financial benefits, social services, carers' services, the Macmillan information centre, the hospice etc. In fact it was reported to be one of the aspects of the role that CCCs particularly enjoyed. Making relationships with people from other services and having a good understanding of available services helped the CCCs to resolve patients' issues and appropriately attend to their needs in an informed fashion.

> "I think from the onset we got really good support from the programme team, didn't we? [six weeks - induction]" (CCC focus group)

> "We've been to where they store all the wheelchairs. We've had a day where we've been to see where the TC wheelchairs or the hand rails, the crutches, where it's all stored. We think, 'What are we going there for?!' but we've actually made contact with the people that work there, and it helps because you can get things quicker." (CCC focus group)

> "At the hospice as well, I was always of the opinion it's where you go and die, and it was only spending the day there, they do so much, even just the drop-in services that they do and the support especially for carers. It was so much apart from that thing people think of, and to do it first hand and experience it when you are talking to patients, you're giving them the correct information and not just what you thought." (CCC focus group)

The contact with other services that were made during the induction and initial training were considered important for them to carry out a holistic service for patients. However, it was considered that this would not have happened without being part of the Macmillan programme.

> "We wouldn't have had that support if we'd not been part of the wider programme. We wouldn't have had that support from the Trust, that wouldn't have been allowed." (CCC focus group)

> “It has definitely opened doors for us to go out there and have a look and feed it back to the Trust… It’s there but people just don’t know it’s there. By doing that training, we went everywhere didn’t we? We went to social services, we went to the supplies.” (CCC focus group)

> “it’s allowed the time to go and see because otherwise… that time wouldn’t have been allowed. We’ve gone to the continence service and seen how they’ve run it. We’ve gone to the volunteer service in Middlesbrough to see how they’re running, and spend a full day with them.” (CCC focus group)

Knowledge of the pathway including the negative impact of delays on patients

It was important for CCCs to have a good understanding of the care pathways and how services are interdependent so that they could have a rational discussion with colleagues about why it is important to carry out certain activities at specific times.

> “We are aware of the pathway…you’re not just ringing that person up on an extension, you go down and see them so you get that little bit of a bond… You're not just trying to rush someone through, you go down and explain the knock-on effect. ‘We do need this scan’ or ‘can we have a scan before Friday because it’s MDT’. ‘If we don’t he’s going to wait another week’.” (CCC focus group)

Topic 3: CCC Impact

Overview

Some key elements of impact for the CCC roles were time saving for CNSs and the prevention of unnecessary consultations, which has benefits for patient experiences as well as freeing up capacity in the hospital.

- Time saving for CNSs
- Preventing unnecessary consultations

Time saving for CNSs

The time saving realised for CNSs from the CCC roles was clearly reported, particularly in one service that had recently lost their CCC and noticed that it "escalated our workload unbelievably." One respondent stated that it had not saved them time. However, this seemed to relate to a nuance regarding the definition of time-saving. They reported an increase in referrals and a subsequent dramatic increase in their workload, which they felt had negated their individual benefit. However, they reported that:

> "obviously I wouldn't have been able to cope so easily in my role, with the influx in referrals if I didn't have her to do a lot of the things that I would have had to do." (P7. CNS)

Preventing unnecessary consultations

The impact of the CCC roles has been significant in improving speed, coordination and quality of care and patient/family experiences which would lead to improved health and well-being, reduced hospital admission and reduced GP attendance. For instance, the CCCs have time to review cases or make pre-emptive phone calls to reassure patients or arrange signposting or appointments, which prevent a hospital visit.

> "I think in colorectal since being in post we've initiated the CNS is now doing more monitoring clinics to patients, where normally they would go to a consultant's review clinic and take 15 minutes of consultant's clinic. Being in post and being able to help the CNS's we're now able to do a telephone clinic where the patient's at home with a cup of tea, no anxiety about parking and the stress of coming in to the hospital. We can do that over the phone and we do that weekly now to patients that the consultant says they don't really need to come to clinic because we keep them on a follow-up. So, that's saving a lot of money for the Trust, a lot of time for the consultants and obviously anxiety for the patients. By being in this role they're now being able to do that which they weren't able to do before and we send forms to patients to go to the GP surgery to please get your bloods done. So, when we do this telephone call everything's available to us. So, I think that's saved a lot of time and money." (CCC focus group)

Topic 4: Sustainability of the CCC roles

Overview

One respondent was keen to observe that CCCs should not replace Specialist Cancer Nurses. Having a clear job description was considered important from a professional and legal point of view. However, there seems to be potential for further training and developing competencies, which is happening in some cancer specialties. This potential could be important in terms of health service sustainability in an era of nursing scarcity. There seems to be a tension here, which is probably best managed within each cancer specialty from a baseline of core duties, tasks and competencies, which could be incorporated into a career development structure for these roles. The Macmillan branding of the role and associated access to training and support are likely to be important factors in attracting people to the role to assist sustainability and spread of the roles.

Macmillan brand impact on sustainability of CCCs

The linking of the role to the Macmillan brand was considered to be an important factor for training and support of people in the role and for the national spread of the role. Without this connection, it was considered that each Trust would have an individual approach and the role might not be adequately supported within the daily business of the Trust. However, it should be recognised that there are tensions inherent in this connection to the Macmillan brand, which currently could have negative connotations for service users, without appropriate marketing and awareness-raising about the breadth of Macmillan services.

> “But on a personal note for ourselves, being in a Macmillan badge, we've had a lot of advantage from that. We’ve gone on a lot of training with them through the grants we’re doing. Counselling courses at the college to help expand our roles to give us more support in the roles, so we’ve enrolled on level 2 counsellor. We’ve the done the health and wellbeing, the enhanced recovery all through Macmillan courses that we’ll go to. So, for us to develop, that Macmillan badge has really been helpful as well as obviously benefit to the patients.” (CCC focus group)
>
> “And even now we've been in post for 2 and half years, there are still courses coming up that we think, ‘You know, that's going to be really advantage to the role now we know what our role is’. Because at first we didn't know what our role was. So, as time has gone on those courses have been really useful to us, to help build our own portfolio as well, isn’t it? “(CCC focus group)
>
> “I think if we weren’t, we need to be adopted by Macmillan to progress our role because I think if we weren't adopted by Macmillan; Macmillan are paying for our salary, we would get lost within the system as in the Trust.” (CCC focus group)
>
> “I think as well if they’re going to promote it and recommend it to other Trusts, then by being Macmillan-badged it's going to get out across the country and everywhere else rather than just a one Trust promoting it. Having Macmillan support behind it is going to help spread it out there.” (CCC focus group)

More opportunities related to Macmillan post

The CCC role was considered to be attractive to new recruits, which could be a key factor in the sustainability and spread of the role. Indeed the CCCs considered that they had taken a risk in moving to the new role, particularly as it was a short-term appointment, but that it was a worthwhile risk to take. Respondents valued the link to Macmillan and felt that the roles gave them enhanced opportunities for professional development, they also valued the fact that the roles extended beyond the Trust and allowed them to have direct contact with patients; to feel that they were making a difference to people's lives. Specifically, the role had significantly increased their knowledge of available services and thereby improved their ability to improve patient services.

> "I think as well by taking that risk you're obviously in your own little comfort zone and we all wanted to be patient- related and just do this job because it sounded amazing. By doing it, it's the best experience I've had. By getting out of that little bubble where I was in my comfort zone I have met knew people in the Trust in that I've worked in 18 years and gone out and met our supplier of the wheel chairs and social services and through this role we've been out into the community and not just in the Trust, and met all these people and all these volunteer sectors that support patients in the community. Through this role we've found that out through Macmillan and through this programme. It's amazing what's out there, it really is isn't it? There's so much out in the community for patients that they don't know, and we didn't know until we took this role on." (CCC focus group)

Topic 5: Understanding of the Community Sister role

Overview

It is assumed that the Community Sisters roles fit between palliative care, district nurse services and hospital, when the patient group don't have complex clinical needs. The roles are patient-centred, holistically-focused and flexible. The Community Sisters can provide clinical care as well as broader advice and support for patients who might still receive treatment from the Cancer Nurse Specialist in the hospital and don't come under the remit of specialist palliative care. The role has evolved to fill gaps in services and to take over from other services, where appropriate. This evolution has largely been driven by the Community Sisters who received training in service development, innovation and leadership to assist with this task.

Regarding the Community Sister roles, it was perceived that patients found it easier to talk in their home environment and it would be a way to overcome apprehension about palliative care involvement. The support for someone who is 'thrown into a sort of a world of new things that they've never experienced before' was considered to be valuable.

Preventing unnecessary hospital and community visits

The Community Sisters were clear about a key aspect of their role being to prevent unnecessary hospital visits.

> "… keeping people at home, keeping them out of the hospital unless absolutely necessary, you've got people travelling to hospital that absolutely do not need to come to hospital… we're trying to maximise that patient's experience and you know maximise capacity here, in the Trust. In that they can give that time to other patients." (P2)

They understood the value of being multi-skilled and having a wide range of up-to-date, regularly practiced competencies to provide a holistic service and prevent multiple home visits from other health professionals.

> "… a beauty, of our roles really because we're clinical as well whereas a lot of specialist or dedicated services in the community are not really clinical. You know, you, for like specialist palliative care, they, if they were visiting that patient that day, they wouldn't do a wound or an injection. In all fairness to them, it's probably because they've not done a wound or injection for a long time. And it's about competence again isn't it but because we keep our skills up, you know we can provide a whole-holistic service, so the clinical, the psychological, the emotional, the everything. So we do take a lot of time off them in that sense, in the referrals-on that we make and you know and some of them will say, "Oh fabulous, [x] has been to see that patient today, so that's given me, I can now pick up that new patient, that needs a new leg ulcer dressing or something because [x] has took that patient off me", so I think I'm anecdotally you know, a lot of the community nurses would say "Oh yes, they save time." (P2)

Evolution of the role

The role has evolved, and the Community Sisters have been important in developing the role. They have valued the autonomy, despite finding this somewhat ‘daunting’. They also appreciated the support and ‘back-up’ provided by management and project leaders.

> “…management and the project leaders have been excellent really, in giving us that like a free reign… To develop and mould the service and been really open to our ideas and suggestions and … backing us up with things that we need, how we want to take it forward. So it has been very sort of innovative. We've had that flexibility… I've never set up a new service before…it has been very daunting…Very, very emotionally, personally, up and down …” (P2)

The initial plan to provide Community Sister services that were based in GP practices was quickly abandoned, as it proved not to work very efficiently. This was perceived to be due to GPs and Community Nurses not fully understanding the role, being restricted to only seeing patients on specific GP lists, and the service not fitting into the way that GP practices work. However, as they continued to work with primary care services, attitudes and understandings of their roles have gradually become more closely aligned.

> “so initially our role was very much about the GP focus, about sitting in GP practices, there was certain GPs practices that were allowed the programme and we were, could only see their patients and to be honest that didn't work very well, at all because I think they just struggled to understand the concept of the role really and what could be seen as palliative and what was not palliative which for me is still a big boundary because you can have patients who are palliative and they may be palliative for 5 or 10 years, I mean obviously your palliative simply means we can't treat with curative intent but we can pause and control that disease … and it was very hard getting the GPs, and actually in the beginning, community nurses to grasp that concept. And that did take a long time.” (P2)

On the other hand CNSs understood the need for the role, which filled a gap in services that was not being filled by Community Nurses. This was largely owing to the flexible referral criteria for the Community Sisters and the potential for developing ongoing relationships with patients, so that they did not become lost to services. However, Community Nurses required specific clinical tasks in order to be referred, and once the clinical need was addressed they had no ongoing remit; responsibility for ongoing care was retained by the GP.

> “Our clinical nurse specialists here thought it was wonderful from the outset, the majority of them did anyway. Because they knew that, they would see patients in clinic who they would just, that person might not have a particular clinical need, so they might not have a wound or need an injection but they're just worried on their own in the community – they might lack support, live on their own, you know, there are frequent people who don't attend appointments, you know and they just wanted someone to oversee them in the community and traditionally that can be really difficult to articulate in their referral to a community nurse because- and again I would know, because a community nurse would pick that up and go “Oh I can't just go in there to hand-hold, I don't have enough time” you know, there's no, you know,

> they might see that patient once and say “here is our number if you want it” but then the patient doesn't really engage with that because it's taken them a lot to pick the phone up and speak to someone”. (P2)

The roles still have capacity to evolve further, through the development of additional competencies such as managing chemotherapy treatment in the community; thereby preventing patients from having to travel long distances for procedures that could be performed at home. However, the Community Sisters have experienced some resistance in accessing training from hospital-based services.

> “It's competence issues as well. But we are kind of willing to learn that kind of competency to get out there and help these patients who have to travel, some of them a 100 plus more round trip to take off chemotherapy bottles and things and we want to help that, we want to help the patients, it will take a lot of pressure off the units as well, it will take a lot of pressure off the wards. But even when our manager, when we've gone to our manager and said you know we've tried all we can from our level to get in there and we saying “Teach us! We want to learn the competencies, we want you to sign us off to do that”. Even when our managers gone there, she's been met by resistance.” (P2)

Similar to the CCC roles, patient perceptions of the role are related to the general belief that Macmillan services are for end of life only. However, once they had understood the new roles, the connection to the Macmillan brand was reported to reinforce their appreciation of the service.

> “I think it can be difficult because you know, you have patients who fortunately for them, don't know any different. So they're quite a new diagnosis and we pick them up and we've always been involved in their care. So they don't know any different … To the majority of them think it's a wonderful service and again, I think we've done you know, you get a lot of patients who say, you know well I thought Macmillan were fabulous anyway but I think they're even more fabulous now because we always thought it was about death and dying.” (P2)

Topic 6: Community Sister connection with other services

Overview

As mentioned earlier, the Community Sister role is dependent on good connections with other services, particularly for referrals. For instance, district nurses might recognise a patient that does not fulfil their own referral criteria, but would benefit from some extra support.

Although the majority of the participants believed that the role supports patients with their emotional and psychological needs in the community, the Community Sisters carry out some clinical work in the community with patients with less complex needs. Integration issues are therefore complex, and have been subject to a great deal of development. As described above, being aligned with GP practices does not seem to be a useful solution. However, close working with GPs, District/Community nurses is clearly beneficial to provide continuity of care whilst also carrying out some routine clinical tasks during a visit, which also involves a more holistic focus and psychosocial support. Close working with CNSs and the CCCs is also a critical aspect of the role. Some of the working practices adopted by intermediate care services to integrate with primary, community and acute services might therefore be usefully adopted.

Different definitions of integration and lack of integration with community services were reported to be problematic, particularly regarding the community health workforces' lack of understanding about cancer services.

> "A lot of them talk about integrated care, other community professionals but actually they're not integrated at all, there's still that divide between you know the community nurses really don't know what's going on in here, they rely on what the patient tells them." (P2)

This section is organised into the following themes:

- CCCs and Community Sister relationships
- Relationships with other health professionals
- Barriers and facilitators for integration

CCCs and Community Sister relationships

The reporting of the relationship between CCCs and Community Sisters was inconsistent. Whilst some CCCs reported being responsible for referrals to the Community Sisters, the Community Sisters did not report the development of strong relationships with CCCs. This could be explained by the CNSs playing the role of intermediary; so that the roles are indirectly integrated. This assumption would also fit with the boundaries placed on the responsibilities of the CCCs, so that they did not operate beyond their remit or expertise.

> "We don't tend to have a lot to do with cancer care co-ordinators I'll be honest, I think again we would have liked, have had more to do with them and think that they probably, there's probably patients that they could refer in to us … but it tends to be, you know it's more, our contact is more with the specialist nurses, here, you know the cancer care co-ordinators work for them so the connection is still there." (P2)

Relationships with other health professionals

> "Now to me the working relationship should be better in that when they are discharging patients in that, in them circumstances [01: They should let us know] they should let us know and she'd refer back in to us. But I think what they say is as long as they've got district nursing involved, they've got somebody but the district nurses can't meet their, their additional needs other than their clinical needs, they don't have the time to do it." (P2)

The link to hospital Consultants was one aspect of the Community Sister role that was considered unique in a community setting. Whereas District Nurses tended to rely on referring back to the GP in order to then process a referral to the hospital, the Community Sisters were able to use their contacts at the hospital, especially Consultants and CNSs, to make appropriate referrals directly to the hospital. In one example this resulted in a rapid admission for a 'poorly patient'. The Community Sister is then notified when the patient returns home, so that they can resume community-based care. This is one way in which the role is able to transform pathways to provide rapid appropriate care to prevent patients experiencing more extreme crises.

> "And as well, I think a lot of the district nurses tend to rely on their GP's, whereas we can ring the consultants up, we can get appointments booked forward, if a doctor's requested a scan we can ring up and say we want it urgently … We have like little bit of control and power over that, rather than just referring the patient back to the GP and then the GP has to initiate it from the beginning. Whereas… if there is a problem with that patient, speak to the consultant and we can get appointments brought forward, so it's preventing time for the patient." (P1)

> "If somebody's unwell we've got the good strong connections… we can pick the phone up to our colleagues here, so our acute oncologist specialist nurse helped me deal with a poorly patient. Within an hour the patient was brought in to hospital, staying overnight on a ward, fluids, bit of a rest and recharge and he's back home. The ward will let me know he's back home and I'm gonna see him tomorrow to review. If that patient didn't have anyone in the community and actually he didn't, he was very much reliant on his GP that would have been a very very different situation." (P2)

Barriers and facilitators for integration

There was an assumption that the Community Sister role could be perceived as taking over existing roles, or crossing boundaries with others' roles, which could be unwelcome; thereby creating resistance from established roles.

> "You're always going to get these people who put barriers up to any new roles for fear of us taking over their own role and putting them out of a job and that is absolutely, it's not going to happen from our point of view… It's improving the patient's experience." (P2)

> "So yeah I think with the integration it's more barriers from the community side of it, to accept us more because there's still that belief that, "Why are you important? We've got community nurses." And it's, it's quite an eye opener really … what people think community nurses do with cancer patients, that actually the majority don't because they don't have the time to do it." (P2)

A key facilitator for the successful integration and acceptance of the role is the making of incremental changes to ensure that the Community Sister service is clearly different to other available services. This is an aspect of the role that might require local tailoring if adopted in different settings.

> "We have… tweaked it haven't we as we've gone along. And I think a big part of it is making sure that our service is very different from other services and kind of like not stepping on other peoples' toes. … I mean you've got your community nursing teams, we know they're very clinical as well and then you've got your community complex specialist palliative care patients when they get referred on, but quite often our patients are newly diagnosed that only really have access to acute specialist nurses, GPs and consultants so we're…there at the beginning, building bridges between primary and secondary care and supporting patients right from the beginning. Ideally with a curative intent but we know it doesn't always work like that." (P1)

However, a tension with this arrangement was reported in situations when patients require complex palliative care and require referring on to a palliative/end-of-life service. This can require the Community Sister to hand over to another service, sometimes after working with the patient for a number of years.

> "We need to be able to establish that when somebody's palliative but they do require, symptom management, complex needs, we then pass them over, don't we? Hand over, we do referrals and we try and pull out which is, has been a bit of a challenge for us, especially when you've known somebody for two years and you're kind of like passing them on, it can be a bit difficult but we need to make sure that we work and we don't step on peoples' toes. We keep the services separate but we kind of like, work together." (P1)

Another tension in providing differentiated services was reported for aspects of the role that the Community Sisters believed could be expanded, particularly when these are currently provided by others. A specific example that was mentioned involved resistance from chemotherapy services for providing chemotherapy support in the community.

> "We could support the chemotherapy unit a lot more than what we are at the moment but there's a lot of kind of barriers there that even our management have struggled to break down … that's one of the things we know we can develop this service so much more and I think … that's quite a simple solution." (P2)

The link between hospital and community services is supported by having close relationships with hospital-based cancer services and having access to hospital and community health care records.

> "Being the kind of dedicated cancer nurses to provide that link between hospital and home and also provide that link from the GP and any other professionals that are involved in that patients care at home… we sort of better link the other members of the multidisciplinary teams in the community, we… provide that link between hospital and home … and we're well linked in with the clinical nurse specialists as well… we're in constant contact, we know exactly what is going on with the patients, we have access to the hospital notes as well as the community notes." (P2)

Topic 7: Community Sister impact

The Community Sister roles clearly fill a gap in services for people affected by cancer and have created a place for additional elements to be added to the role in order to further transform cancer pathways and improve patient experiences. They have clinical expertise, but are not simply task-based. As such they can help to alleviate pressure on family members and provide reassurance, support and guidance for patients; helping them to be active in their experience of cancer services rather than passive and poorly informed recipients of care.

The time saving realised for CNSs from the Community Sister roles was more difficult to articulate than for the CCCs. This relationship is probably problematic to observe due to the separation between the community and hospital services. However, some savings for CNSs were recorded in the Community Sisters' IMs.

Some elements of quality of care that might be impacted on by the Community Sisters were provision of additional support, better understanding of hospital treatments, prevented GP and hospital appointments and preventing the need for patients to make phone calls to consultants' secretaries; generally to help join-up services and give patients a better understanding of what they are doing.

An important area of impact for the Community Sister role is improvement in patient experience, which is made possible by the holistic nature of the role and having time to spend with patients to discuss a range of concerns that they might have.

> "I just think sometimes the patients don't tell the district nurses things because we're the cancer nurse and they can talk to us a little bit more can't they? About it. Again I think it's about the time." (P1)

Topic 8: Implementation of the Community Sister roles

Overview

The main challenges facing both CCC and Community Sister roles are others' understanding of the role including health professionals and patients' perceptions. For the Community Sisters, flexibility to develop the roles has clearly been useful. However, setting up and maintaining communication routes and appropriate referral pathways for this type of role is a challenge. The Community Sisters have taken on marketing and promotion of the role. However, these activities would be facilitated by long-term security of the role. This section is organised into the following themes:

- Evolution and clarity of the Community Sister role
- Expanding the role
- Integrating with existing services
- Marketing and promotion

Evolution and clarity of the Community Sister role

Originally there was confusion reported between how the Community Sister role and district and palliative specialist roles would work together. As would be expected with a new 'linking' role, initially some referrals were reported to be inappropriate. However, these issues are now considered to be largely resolved. The Community Sisters have a base of broad skills. However, opportunities for developing more specialist skills over time were acknowledged. Indeed a two-way process of learning with the CNSs was recognised.

Expanding the role

Depending on the security of the role, the Community Sisters' are open to further training to improve their competencies in order to take on more clinical responsibilities, but due to the cross boundary nature of the role they are likely to work with different types of cancer and learn more skills over time. However, some hospital services appear to be more open to supporting the development of competencies than others. The role provides the Community Sisters with opportunities to work with the site-specific clinical nurse specialists and seek advice from them while at the same time CNSs can learn a different skill set from them; understanding how to support people at home and in the community through a mutual development process.

Integrating with existing services

Regarding integration with other services, respondents indicated a balance of benefits and drawbacks of particular areas of managerial expertise. Hospital-based experience helped to introduce the CCC role and to ensure that Community Sisters were integrated with CCCs and hospital specialist services. However, this also meant that Community Sisters were relied upon to a greater extent to plan and develop their roles. Whilst this was reported to result in some anxieties for Community Sisters, it did give them a sense of ownership of the roles and allowed them to have an influence in developing the role to their individual strengths and preferences and their understandings of local community services.

The Community Sisters that were recruited had extensive experience of working in the community. This resulted in a service development process that was led by the Community Sisters and flexibly supported by management. Whilst this has resulted in some benefits, the marketing of the roles to other services at a managerial level was considered to have been challenging; owing to this specific mix of experience within the team.

> “Our manager is extremely supportive ... she has no community experience at all. And these roles, when they were formulated… they had a vision of how they wanted to see it in community and how they wanted to see the roles be, but … this has not been done before. And obviously a lot of the, a lot of the management side of it had not worked in community, they don't know how things work in the community… so, they selected … a lot of people at interview who could bring that community expertise in… our direct manager and project managers and things, they're really good in that they're very open to us coming back with our honest ideas, what will work, what won't work, what we can ask for. But they have also been...kind of, held back a little bit themselves when they're out there trying to push our roles with other people.” (P2)

However, these challenges were addressed; as Macmillan supported the Community Sisters to develop their knowledge and skills for service development, leadership and innovation and helped them to network with other services.

> “And we get, we get a lot of support, I know initially when we first started, there was a lot of support not only just for sort of clinical and, and cancer expertise training but a lot of training about the development of new services, about leadership, about you know, innovation and they got us really well connected with other services that they've set up and funded, so it's fabulous from that point of view as well.” (P2)

Marketing and promotion

The Community Sisters self-initiated a marketing campaign to promote the service. However, the continuation of this is reliant on them feeling secure in their roles.

> “And then in December last year we did a presentation about the service and from then, when we kind of tweaked the criteria a little bit and then spread the word of what kind of referrals we need, I found that with the likes of colorectal and breast they just kind of like started to refer a little bit more and I think if we knew ourselves that we were going to be kept on we'd be a little bit long or substantive then we could again start doing more presentations, going out to the GPs, just really opening the role up a little bit more to people.” (P1)

Topic 9: Sustainability of the Community Sister roles

The Community Sisters demonstrated dedication to their roles and were very keen for these to receive continued funding.

> “But we, we just really really, we just love our jobs, we're really really dedicated and passionate about the role and we're absolutely desperate to be funded and we're willing to put the work in.” (P2)

As marketing of the service is in relatively early-days, different approaches are being developed and it should be assumed that the service does not have a particularly high profile. However, as other professionals become aware of the role, particularly as it is filling a gap in current services, there is the potential to experience capacity issues and resurgence in inappropriate referrals (which might require ongoing monitoring).

In common with the CCC role, the public perception of Macmillan is related to end-of-life care, rather than early intervention with curative intent. This could be a barrier to uptake, and is reported as a common barrier that the Community Sisters need to overcome prior to service delivery.

> “I think, one of the, one of the barriers that we've had haven't we, is that, you know, really our role is about new diagnosis and, treating it with curative intent. So then when we arrive and we're Macmillan badged, patient has that “Hmm?”… You're a Macmillan nurse, I thought my treatment was curative. And, to be quite honest I think in the last two years, our service has done a lot to break down that barrier and that image of Macmillan.” (P2)

Topic 10: Patient Experiences of Community Sister Roles

Summary

The key themes discussed by service-users were:

- The limited coverage of the roles
- The need for the role and filling a clear gap in services
- The ability to discuss broad topics with the Community Sisters
- Some specific activities, such as making treatment recommendations and intervening to solve problems with other services
- The holistic, family-based support and opportunity to develop close relationships was highly valued
- Patients reported having to overcome preconceptions about Macmillan services being involved with end of life care
- Outcomes included being able to socially and emotionally deal with the illness and to resume a more normal life of activities

It was clear from the respondents that they had a very well-defined understanding of these roles. They viewed these as occupying a very obvious gap in services that were not being provided elsewhere. Key elements of the roles were continuity of care and the ability to build up strong relationships. The holistic remit was very important, offering the opportunity to discuss a range of topics that went beyond the fairly rigid clinical service provision experienced elsewhere. The ability to have someone to talk with about concerns, without 'unnecessarily upsetting' family members was highly valued.

There were reports of specific ways in which the Community Sisters had helped to resolve problems or provide support through difficult times. Importantly, the presence of the Community Sisters was reported to provide social and emotional resilience in a number of ways:

- In a close family environment they allowed family members to take a 'step-back' from trying to provide all of the care and support, and to resume some of their normal activities
- For people without close family members they provided a valuable 'life-line' for support and help to make important decisions
- One of the participants related the support that they had received from the Community Sisters to their ability to now provide support for someone else affected by cancer

All of the participants wanted the Community Sisters posts to remain. However, they were aware of the lack of resources during the pilot phase, and wanted to see more of the roles being developed:

> Iv: Would you like the [CCCSis] role to stay?
> DoSU3: Definitely
> SU1: Absolutely
> SU2: And need adding to as well
> SU3: Definitely need more
>
> "You couldn't take them away, they've just been invaluable" (DoSU3)

Theme 1: Limited coverage of the roles

The participants were unanimous in the opinion that there were not enough of the Community Sisters roles for the demand. In fact, having more Community Sisters was the only improvement to the role that the participants could suggest.

> Iv: So the only improvement would be
> DoSU3: More, you need more
>
> "They are so needed, there should be more" (DoSU3)
>
> SU2: You definitely need more feet on the ground for sure
> SU3: They never rush you, they've always go the time…they're there for as long as you need them for and you know there's only a couple of them, you think flipping heck, could do with another six

The participants were concerned that the lack of coverage might impact on the wellbeing of Community Sisters. Questions were asked about what support there was for them.

> DoSU3: [CCCSis] is going out supporting all these people but she's a one-man-band
> SU2: Makes you wonder how they cope, doesn't it.

Theme 2: Need for the role

The participants identified; emotional support, allowing them to talk about things that they could not discuss with others, provision of advice, helping them to navigate health services and assistance in making decisions as some of the key needs that the roles met. This was in contrast to the purely functional clinical services that they accessed.

> "someone got in touch today and started talking about my medications…but it's not really my medication that I want to talk about, it's my mental and emotional support I want. I know that any given circumstances where I need medical help, it's there in the form of consultants and doctors" (SU1)
>
> "earlier this year we'd run out of tablet options and the only option was chemotherapy, and I decided to not go down that route. But on all these occasions, I'd nobody to talk it through with, nobody to discuss, nobody's shoulder to cry on. I've had none of that, and that's been a big gap, and I know the people are there, because I've had 3 of them, but they've all gone off sick" (SU1)

Interestingly, one of the participants recognised the differences between Macmillan palliative care services and the Community Sisters roles:

> "the surgery was closed …so I rang the Macmillan people at Northallerton and she said 'oh I'm not sure I can help you'…how can she help, she piped up 'we still do palliative care'. I thought that's not what I need at this particular moment." (SU1)

Theme 3: Broad topics of conversations with Community Sisters

Respondents reported being able to ‘talk about anything’ and raise any problems; particularly regarding issues that they found it difficult to communicate with family members about. They were grateful for the honesty and experience of the Community Sisters.

> “It was perfect, because we could talk about anything, and built up a relationship. Any problems I had or anything I wanted to discuss, she was there for me” (SU3)
>
> “There was someone different who she could talk to. It’s alright wanting to talk to your family, but there will have been things Mam would have wanted to talk to [CCCSis] about, that she wouldn’t want to worry her family about, and [CCCSis] could just reassure her. And she’s been amazing, absolutely amazing” (DoSU3)
>
> “You don’t want to tell your own family, you don’t want to worry them (SU2)
> It’s true, you don’t want to upset them unnecessarily” (SU1)
>
> “’But you’re bottling things up’ and we had like tears. And I could see she was like mount Vesuvius, she was going to go any minute …she needed someone to talk to that it didn’t matter if she got upset, it didn’t matter if she wanted to say to somebody ‘this is bad’, but she wouldn’t say it to me, because she didn’t want to worry me” (DoSU3)

They were grateful for the honesty and experience of the Community Sisters, even if this was difficult to deal with at the time:

> “There was no lies, there was just honesty... [CCCSis] said ‘it’s got to be your mum’s choice’. And I was like ‘WHAT’?...at the end of the day, she’s looking after her own patients and what they want” (DoSU3)

Theme 4: Activities of Community Sisters

There were reports of some specific activities that were carried out by the Community Sisters, such as: support through difficult clinical procedures and treatment decisions, recognising medical problems and making treatment recommendations, and intervening to solve problems with other service provision.

> “[CCCSis] was waiting for me when I came in. She was there holding my hand when I had these cameras, and talking to me. I didn’t like it when I had to have them twice, horrible things. She was there every time I had to come” (SU2)
>
> “She would just sit and talk, ‘what drugs are you on, and are you happy with them’ and one of them, I’d lost a bit of weight, I’d got a sick bug… and I lost about a stone in a week and she said ‘I’m going to ring your doctor’ …’have we thought about steroids’ and the doctor hadn’t thought about steroids…So it’s a combination of supporting what you need, your medication, but also your emotional needs and making decisions.” (SU1)

> "Just not going down the chemo route again…it's death itself. Since April, I'm not on any medication at all just on pain killer, and it's I've been brilliant and it's because I've de-toxed… And she was supporting me in that," (SU1)

> "We got authorisation to be able to order the dressings…but then we'd go to the chemists to pick them up and the chemist would be like 'why don't you order through us?' and then the doctors would be saying 'you need to order through us' and it was like a battle field….so [CCCSis] got everything written down, everything sorted and as soon as we got her on board, we never had any more trouble; absolutely fantastic." (DoSU3)

Theme 5: Relationships with Community Sisters

The holistic, family-based support was valued.

> "Within the first 5 minutes of [CCCSis] being in the house, her presence changed the whole scenario…straight away you clicked with her…The way she spoke to Mam…'I'm not just here for your Mam, I'm here for your Dad, I'm here for you, I'm for your brothers and for your children'. I was like 'really!'…that was fantastic." (DoSU3)

It was important that the Community Sisters provided time to talk to the PABC to the extent that the family member was no longer wanted, which helped them to feel that they did not have to provide all of the support.

> "There's a lot of guilt. You've got cancer and you don't want to tell your family. I got to the point where I'd kept it secret so long I actually couldn't tell my family. I went through Chemo, I had a mastectomy, and then radiotherapy [CCCSis] was always there." (SU3)

The respondents reported forming friendships with the Community Sisters and looking forwards to their visits.

> "At first it was 'Can you stay whilst [CCCSis] is here' then I was kicked out literally; 'oh don't come in the morning [CCCSis] is here'. And she formed a lovely friendship with her. It's just amazing to see, Mam actually gets excited, happy to see her." (DoSU3)

> SU3: [CCCSis] was coming every 2 weeks and then went to every month, then I saw her beginning of November and she said 'I'll see you in the new year' and you go 'YES'
> SU1: Yes, somebody you look forward to seeing; somebody who knows you. Not intimately, they don't have to be best buddies; somebody who knows your case and know what you're going through.

Continuity of care was clearly important. Having to repeat their history to a succession of service providers was reported to lead to situations where they would stop seeking help.

> DoSU3: …It's having that same person you built a relationship with. You build that trust…If you've got a different person …they don't know my history.
> SU3: You've got to start all over again.

> DoSU3: Yeh, start all over again, in the end it would get to the stage, just like you said ‘it doesn’t matter’. But when you build that bond with someone, you want to keep it.

The experience and training of the Community Sisters was highly valued. As discussed earlier, this relates to their holistic approach, relationship-building skills, honesty in difficult situations, ability to discuss issues that others might try to avoid and understanding of outcomes and service delivery processes. Overall, this was summed up as having the experience and understanding to be able to deal appropriately with any situation.

> SU3: You want someone you can bond with, to relate to …it’s difficult to describe the type of relationship you want.
> DoSU3: …They’ve worked alongside so many patients and had so many scenarios that they know how to deal with it and understand it

Theme 6: Perceptions of Macmillan services

Without an understanding of what support the Community Sisters could provide, there was an initial resistance reported, which seemed due to perceptions about Macmillan services being for people requiring end of life care.

> “I the beginning when I was diagnosed with cancer, and Macmillan nurses were mentioned I was quite resistant, ‘I could look after myself’. I put all the onus on my daughter instead of going down that line. Not because I thought ‘there’s the death nurse knocking at the door with a list of undertakers’, you know” (SU3)

> SU3: I can see the difference, what a Macmillan nurse was in the 80s when I worked on District, to what a Macmillan nurse is now. And it’s 100% completely different, the service you get now from Macmillan…
> DoSU3: It’s more of a support network
> SU3: Macmillan nurses then were just palliative care
> DoSU3: That’s why Mam said ‘no’ she didn’t want any district nurses in, she didn’t want anyone

> People hear the word Macmillan nurse and they think ‘oh god, I’m not long for this life’ and that’s not the case. …They’re life giving (SU3)

The public profile of Macmillan services was reported to rather low-key, especially when compared to awareness of local hospice services. This was also related to the previously discussed issue of limited coverage.

> SU1: in our area the….hospice nurses seem to get better press, because the Macmillan nurses are not visible enough
> SU2: That’s right
> SU1: The praise they get is unbelievable, because there’s more of them about

> SU3: I think the Macmillan service itself needs a lot more recognition and a lot more bringing into the public attention…you see the odd, you know September when they have the Macmillan

> baking, yes it's advertised then and a few odds and sods, but other than that you don't see anything. I think a lot of people if you said to them 'what does the Macmillan service do?' nine out of ten of them would say they look after you when you're dying, coz that's the negativity you know

Theme 7: Outcomes and impacts

One of the key reported outcomes was the ability to socially and emotionally deal with the illness and to resume a more normal life of activities and day-to-day family relationships.

> "That one person made such an impact on my Mam and we all saw it as a family. …her attitude changing, her accepting, 'yeh!, I've got cancer, I can deal with this', and that changed the goalposts because we could see a difference in Mam, we could see her starting to get on with her life, I could see my dad relaxing and not walking on tenterhooks, because if she wanted to talk, she'd talk to [CCCSis]. And I started moving away as well and saying 'you talk to [CCCSis]' " (DoSU3)

> "…and you can see the difference it's made in all of our lives…as soon as she said I'm here for your dad as well, because men don't talk. And dad would sit and have a coffee with you and [CCCSis] and chat, any concerns or if he was worried, he would then be able to say 'is she doing okay?' and just [CCCSis] saying 'she's doing great' made my dad relax." (DoSU3)

> "Knowing Mam was getting support was enough for me, and I hadn't been to the gym for about 5-months because I couldn't function, I couldn't sleep, I just couldn't…and going back to the gym helped me." DoSU3

One of the respondents was now managing so well that she was able to provide support to one of the friends that she had made at chemotherapy clinic.

> "…and [CCCSis] said 'do you want me to go and see her. Give her my number and she can contact me'? The offer was there straight away. …It's fallen on us to support her" (SU3)

Work package 2: Quantitative Evaluation Findings

Staff costs

The Macmillan Team was set up with a total of 14 staff, as detailed in Table 1 below. Central support staff are assumed to input 10% to the project. The intervention was considered ‘fully-live’ from October 2016 to the end of June 2018 (total 21 months); costs and benefits have been calculated for this period.

Table 3: Staff profiles and cost during 21 months of the intervention

Job Title	Number of staff	Salary with on-costs	Time period	Months	Cost per time period	Cost per role for 21 months
Cancer Care Coordinator	7	25,262	*Oct 16 – Mar 17*	*6*	*8,8417.00*	
Cancer Care Coordinator	7	26,129	April 17- Mar 18	12	*182,903.00*	
Cancer Care Coordinator	7	28,821	April 18- Jun 18	3	*50,436.75*	321,756.75
Community Sisters	3	35,200	*Oct 16 – Mar 17*	*6*	*52,800.00*	
Community Sisters	3	36,850	April 17- Mar 18	12	*110,550.00*	
Community Sisters	3	37,418	April 18- Jun 18	3	*28,063.50*	191,413.50
SUB-TOTAL						£513,170.25
Macmillan Head of Cancer Services	0.1	53,644	*Oct 16 – Mar 17*	*6*	*2,682.20*	
Macmillan Head of Cancer Services	0.1	59,236	April 17- Mar 18	12	*5,923.60*	
Macmillan Head of Cancer Services	0.1	59,236	April 18- Jun 18	3	*1,480.90*	10,086.70
Macmillan Service Improvement Lead and CCC Line Manager	0.1	51,205	*Oct 16 – Mar 17*	*6*	*2,560.25*	
Macmillan Service Improvement Lead and CCC Line Manager	0.1	61,060	April 17- Mar 18	12	*6,106.00*	
Macmillan Service Improvement Lead and CCC Line Manager	0.1	62,924	April 18- Jun 18	3	*1,573.10*	10,239.35
Macmillan Programme Support	0.1	24,320	*Oct 16 – Mar 17*	*6*	*1,216.00*	
Macmillan Programme Support	0.1	24,320	April 17- Mar 18	12	*2,432.00*	
Macmillan Programme Support	0.1	26,538	April 18- Jun 18	3	*663.45*	4,311.45
Lead Cancer Nurse (Trust)	0.1	69,168	*Oct 16 – Mar 17*	*6*	*3,458.40*	
Lead Cancer Nurse (Trust)	0.1	73,495	April 17- Mar 18	12	*7,349.50*	
Lead Cancer Nurse (Trust)	0.1	75,736	April 18- Jun 18	3	*1,893.40*	12,701.30
SUB-TOTAL						£37,338.80
TOTAL						**£550,509.05**

It is estimated that the salary (including on-costs) for all staff members required to develop, implement and deliver the service over the 21-months between October 2016 & June 2018 was £550,509.05. These costs include programme management and administration (£37,338.80), which would not be required once the delivery model is embedded as business as usual. The costs for only the CCCs and Community Sisters that would be required to deliver the service on an ongoing basis (post implementation) would be £513,170.25 for 21 months (£293,240.14 per year).

We were not able to accurately estimate the development and implementation costs. However, a senior member of the team estimated programme management and administration costs at roughly 9% of full-time equivalent costs of the posts. This estimate has been rounded up to 10%.

Saving time for other staff members

The tasks undertaken by CCC are classified using the distinction of levels 1-4 as detailed below.

Level 1 interventions are regarded as non-clinical, simple problem solving such as general admin, booking transport, typing paperwork.

Level 2 interventions are single patient contacts to resolve a specific clinical or non-clinical problem. This level would be applied to a problem which poses a clinical and non-clinical need for intervention. Examples such as, identifying patients for MDT, completing requested referrals, triaging calls to the most appropriate professional.

Level 3 interventions - Short term involvement for multiple problems. These interventions involve face to face or telephone contacts with patients or carers in order to perform a review, to triage patients to the appropriate professional or to provide support and reassurance.

Level 4- Usually includes interventions for patients with complex problems which require a higher level of problem solving using advanced skills such as MI, counselling and the professional having a greater understanding of cancer and its management.

One of the main impacts of the Macmillan intervention was achieving savings of various health professional's time including CNS, consultants, GPs and others. For example, by undertaking type 1&2 interventions, CCC contributed to savings on CNS time so that they could focus on more complex tasks e.g. type 3&4 interventions. Also, as discussed in further sections of this report, in some cases this created the opportunity to release slots for new activity (such as CNSs carrying out more monitoring clinics, which would otherwise be conducted by Consultants, see page 18).

On the other hand, Community Sisters perform a range of levels of interventions (depending on the needs of service-users), but primarily focused at higher level (level 3 & 4) tasks. Qualitative evidence supports the view that the Community Sisters fulfil a unique role in community cancer care, providing more appropriate care and preventing interventions by other service providers.

Good quality data were not available for the entire 21-month duration of the intervention. However, based on the data collected as part of the Intervention Matrix, it is estimated that over the 18-months between Jan 2017 and Jun 2018, CCCs and Community Sisters contributed to significant savings of staff time as outlined in Table 4 and Table 6 below. Some examples of the types of activities that were recorded as time saving are:

> "Patient has had surgery. I have added patient to post op MDT discussion this week. Saving CNS, Consultant, secretary and MDT time"
>
> "Checked MDT folder to make sure patients' discussed, added to clinics or treatments booked. Saving CNS time"
>
> "Asked by CNS to start treatment summary for the patient which is a record of what they have had done and what happens over the next five years. I start them and then the CNS can complete it"

The savings were estimated assuming that a working day for CNS Acute, Social worker, GP and AHP equals to 7.5 hours; and the Community Nurse equals to 8 hours. The typical A&E admission was estimated to take 5 hours.

Table 4 Savings of staff time (in days) from CCC activities Jan 2017-June 2018

	Lung	**Head & Neck**	**Prostate**	**Colorectal**	**Lymphoma**	**CUP**	**AOS**	**Days saved**
CNS Acute	127.39	100.76	55.37	110.57	113.6	139.22	223.95	870.86
Community Nurse	4.18	3.24	0.16	0.13	0.03	0.42	0	8.16
Consultant	1.44	1.88	2.6	0.07	0.86	0.04	0.18	7.07
GP	0	0.01	2.33	0.03	0.08	0	0.11	2.56
AHP	0	0.08	0.86	0	0	0	0	0.94
A&E Admission	0	0	0	0.02	0.48	0.06	0.02	0.58
Social Worker	0	0	0.11	0	0.16	0	0	0.27
Total	133.01	105.97	61.43	110.82	115.21	139.74	224.26	890.44

The highest savings of staff time were achieved for CNSs, equalled to nearly 871 working days over 18 months. The second-high savings were achieved for Community Nurse, equalled to 8.2 working days, and the hospital consultants 7 working days. In total, nearly 890.5 days of staff's time were saved.

Table 5: The cost of an hour of NHS staff by profession

Professional	Cost of staff (£/ hr)	Monetized cost saving (18 months)
CNS acute	£23.00	£150,223.40
Community Nurse	£21.00	£1,370.88
AHP	£21.00	£148.50
Social worker	£39.60	£80.19
GP	£51.00	£979.20
Hospital Consultant	£75.00	£3,976.86
Sub Total		**£155,799.83**
A&E staff	£122.00	£353.80
Total		**£156,153.63**

It was reported that the Community Sister roles had taken more development time, in terms of establishing the definition of the roles and accurately recording activities. Therefore, cost savings for Community Sisters were estimated from records from 5-months where the breakdown by professions was available. The total saving for 5-months was £588.36. It was assumed from the available evidence that these 5-months were generally representative of savings across the duration of the intervention. These figures were therefore used for estimation of savings for the duration of the intervention ((£588.36/5)*21=) £2471.10.

Table 6: Savings of staff time from Community Sisters activities Dec 2017-Feb 2018 & May 2018-June 2018

	CNS Acute	Community Nurse	GP	Consultant	Total
Hours saved	13.27	1.56	3.87	0.71	19.41
Total £ saved	305.28	32.71	197.24	53.13	£588.36
Estimated for 21 months	1282.19	137.37	828.42	223.13	£2471.10

There is clearly a difference in the magnitude of savings made by the CCCs and the Community Sisters, which could be because the Community Sisters' interventions largely consisted of home visits and where therefore less frequent. The values for time savings for Community Sisters might also be higher than the CCCs. For instance, whilst a CCC might save a GP consultation, a Community Sister would be more likely to prevent a home visit, which would be more costly. The Community Sister roles are also more flexible, in terms of the types of interventions possibly making it more difficult to estimate the impact on other service providers. In common with the CCC roles, it is likely that these records represent an under-reporting of savings.

The cost of an hour of staff's time was estimated by the Macmillan service managers as shown in Table 5 above. When monetized, for CCCs these costs savings equalled to £156,153.63. However, to prevent double counting, A&E savings (£353.80) have been removed from the total, as these are calculated by other methods. Similar to the savings for the Community Sisters, these 18-months of records are assumed to be representative of the whole 21-month intervention. When estimated over the duration of the intervention this is equal to ((£155,799.83/18)*21) £181,766.47.

The total saving for both roles is therefore estimated as £184,237.57. However, it is important to note that these monetary savings would only be achieved if the resources were changed/adjusted accordingly, e.g. ward staff were moved to other positions or new members of staff not appointed.

Also, the evidence from discussions with the managers and qualitative evidence suggests that some of the time savings might be considerably underestimated, especially those related to primary care. For instance, regarding the CCC intervention; the fact that patients did not have to visit their GP each time they needed a referral meant that GPs time was saved prior to the contact with the CCC, rather than as a result of their intervention.

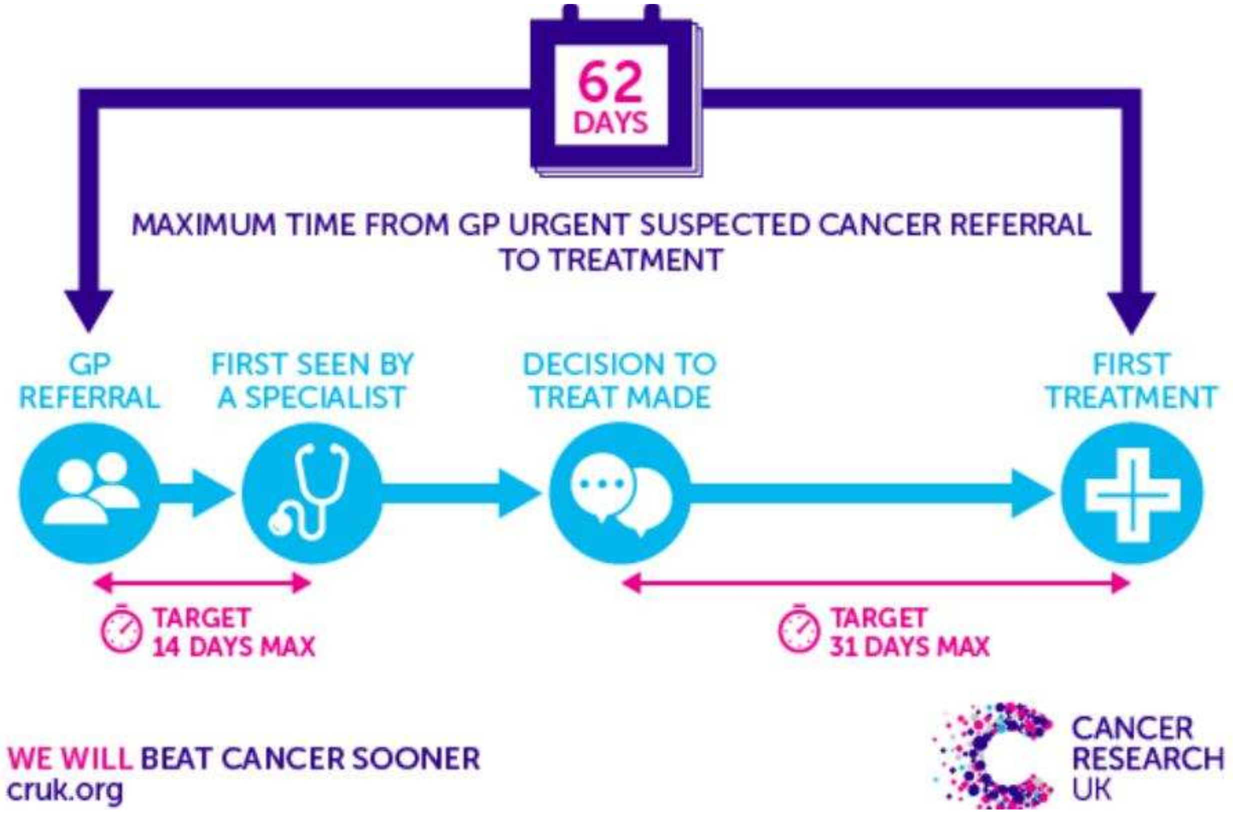
Wider system and patient-specific benefits

The analysis investigated the evidence on wider benefits for the system and patients achieved in all 7 tumour groups.

System-wide benefits: Saving time on 62-day pathways

Waiting times for cancer treatments vary by country in the UK. In England, the 31-day target refers to the target for the maximum time from receiving diagnosis to first definitive treatment. The 62-day pathway in England is defined as beginning first definitive treatment following urgent GP referral.

Figure 3: Infographic of 62-day pathway



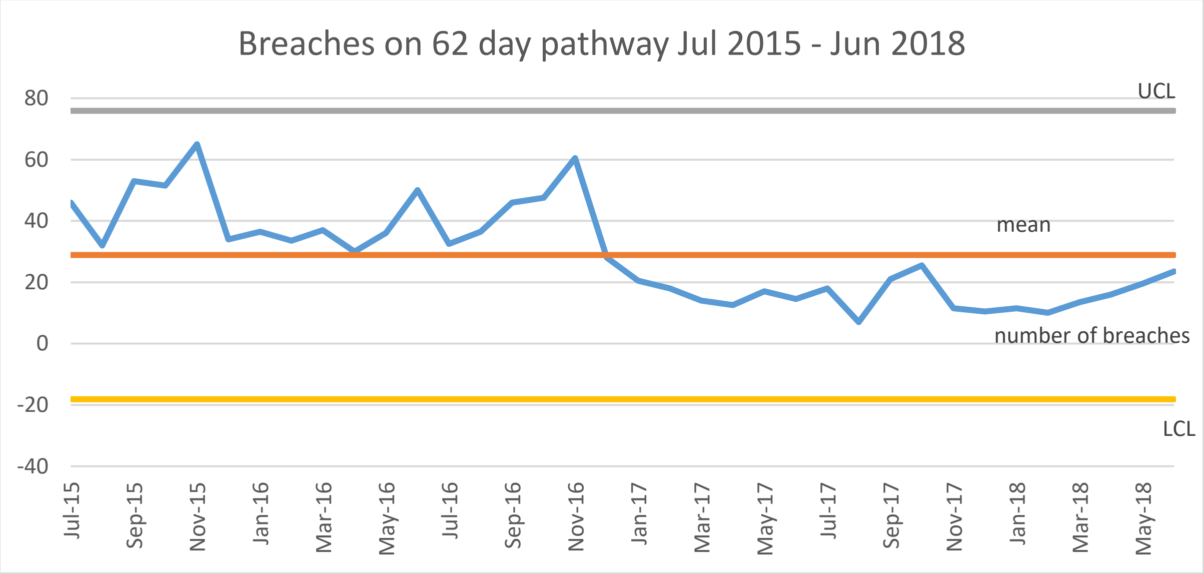
(https://www.cancerresearchuk.org/sites/default/files/cs_report_cwt.pdf. Downloaded 15.01.19)

Compliance with the 31-day and 62-day pathways is regularly reported on within the Trust, and was explored by interrogating routinely collected data. Keeping the waiting times within the limits of the maximum 31-day to receive first definitive treatment following cancer diagnosis and 62-days from urgent GP referral to the beginning of the first definitive treatment for suspected cancer are considered as one of the major quality indicators of cancer care (NHS England, 2017).

In the considered period of time, 84 patients experienced breaches on the 31-day pathway, and 372 patients on the 62-day pathway. On average, the waiting time for cancer appointments extended by 1 day on 31-day pathway and 1.5 days on 62-day pathway. We have explored the 62-day pathway in detail, as this encompasses more aspects of the pathway, is reliant on good coordination and is likely to be the metric that is most affected by improving integration of services.

As shown in Figure 4 below, overall, the number of breaches on 62-day pathway (for five cancer sites; colorectal, lymphoma, head neck, lung and prostate) dropped significantly from November 2016 and remained below the overall mean. This seems promising as the intervention is considered to have been 'fully-live' in October 2016, and the pattern of distribution obeys one of the statistical process control (SPC) zone rules (8 consecutive points falling above or below the centreline) indicating a trend due to assignable causes (Western Electric Company, 1956).

Figure 4: Breaches on the 62-day pathway for colorectal, lymphoma, head neck, lung and prostate Jul 2015 – Jun 2018



When the individual pathways are considered, similar impact is seen in case of 62-day breaches on the prostate cancer pathway (Figure 5) and Head and neck cancer pathway (Figure 6). There is an indication of a sustained special cause variation (i.e. reduction in breaches), shortly after the intervention.

Figure 5: Breaches on the 62-day pathway Prostate cancer

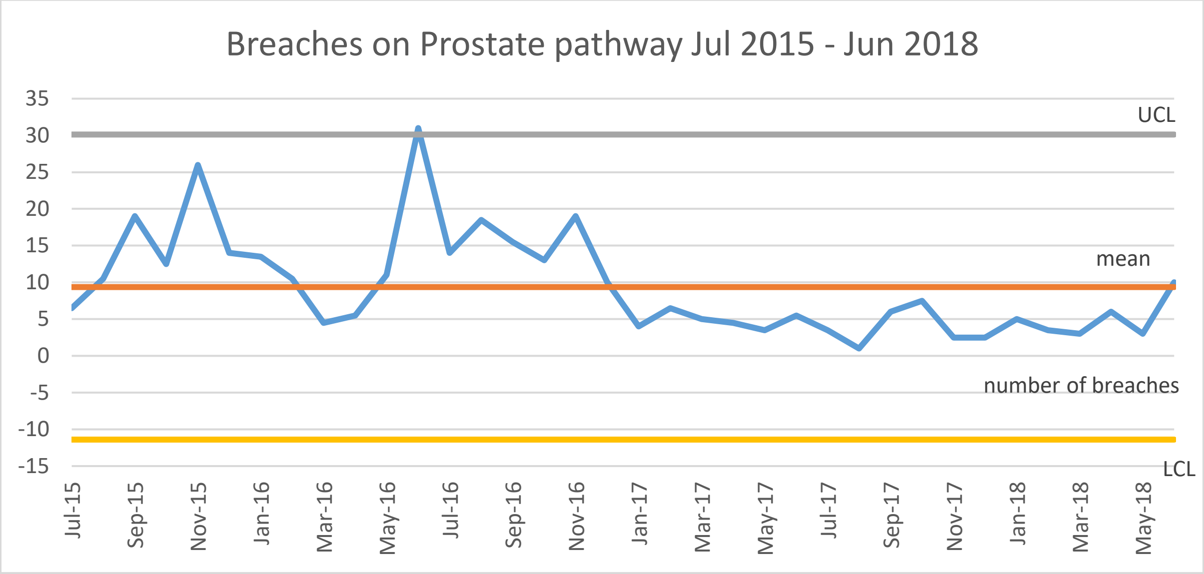
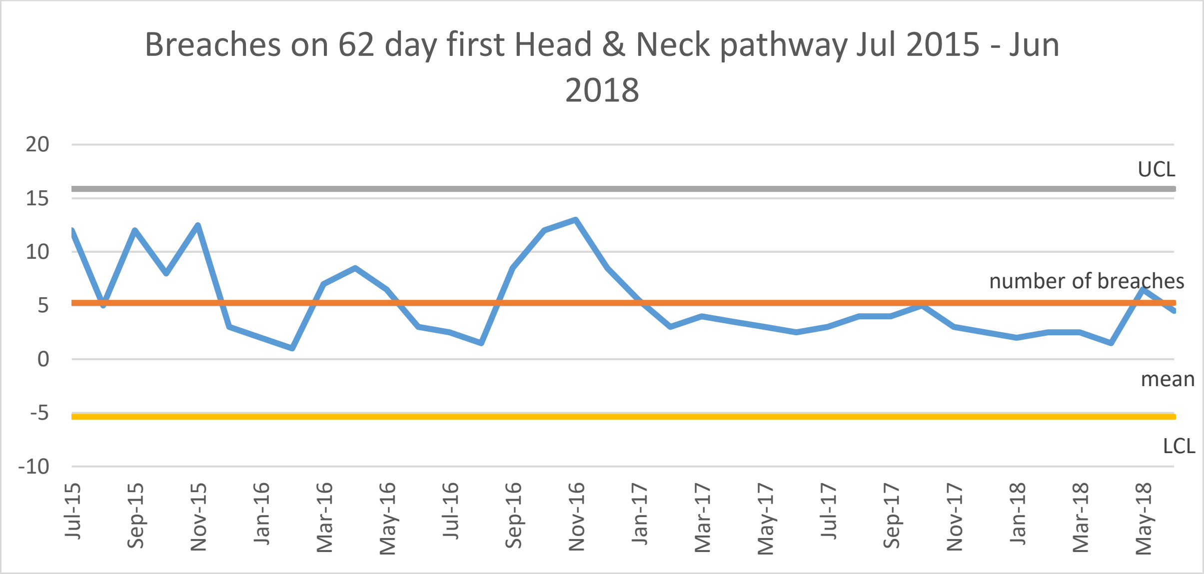
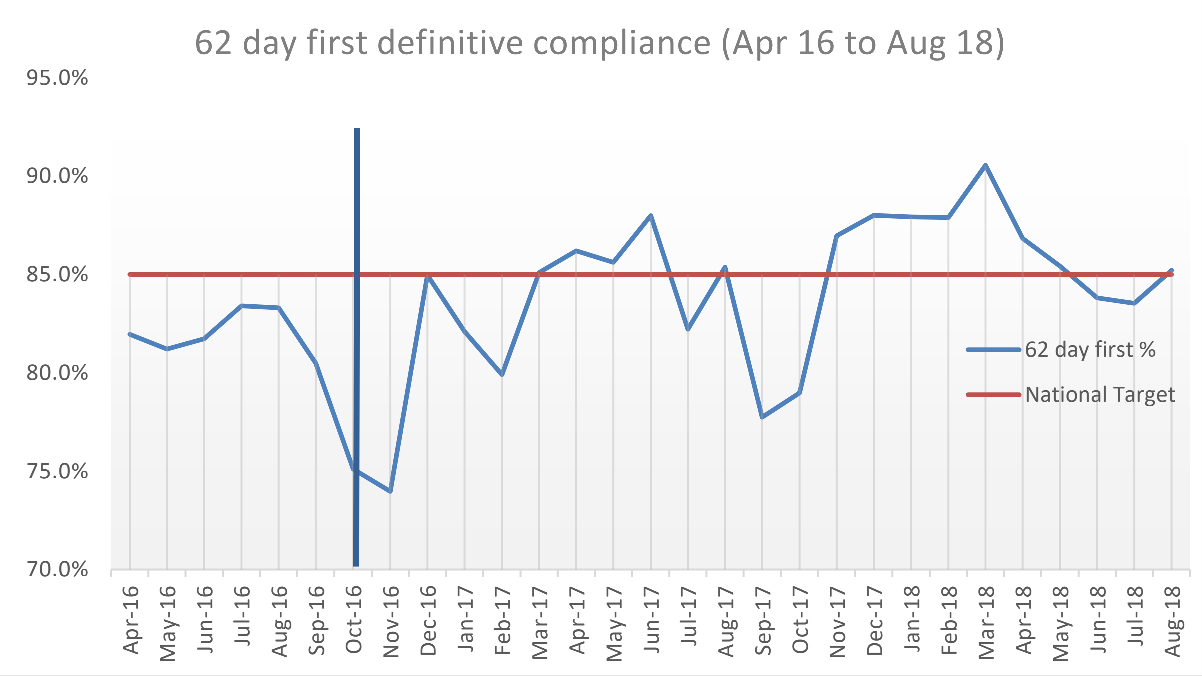


Figure 6: Breaches on the 62-day pathway Head & neck cancer



Following the intervention, compliance on the 62-day pathway national target (85%) measured as a percentage of patients seen within 62 days from referral, achieved 13 months in which breaches were above this threshold as shown in Figure 7 below. There is a sharp increase in compliance from November 2016 (1-month after implementation of the roles) and 85% is achieved in December 2016. Compliance achieved a level of 90% during March 2018, which is the highest point during the observation.

Figure 7: Compliance with the national target on the 62 day pathway (colorectal, lymphoma, head neck, lung and prostate).



Although it is difficult to tell from just over 2-years' worth of data; the August-October drop in compliance would appear to be a seasonal effect. However, the 2017 data (post-implementation) demonstrates a less severe drop in compliance and a more rapid recovery: one-month decline followed by improvement, whereas the 2016 data demonstrates a 3-month consecutive decline.

Additional data is available in the Intervention Matrix to indicate a potential assignable cause for these reductions in breaches. Based on the data collected in the Intervention Matrix, it is estimated that 1012 (11%) of all CCC interventions contributed to savings of time on the 62-day pathway, thus the visible improvement in compliance from March 2017 till June 2017 and November 2017 till May 2018.

The extended waiting times on the 31-day and 62-day pathways impacted not only patients, but also had implications to the Trust. The linkage of funding to targets such as the 62-day pathway is highly controversial as this can limit funds available to improve services and focus on other priorities [APPGC, 2017]. However, as stated in the NHS Five Year Forward View for the purposes of incentivising achievement of the 62-day standard, this measure is linked to an element of the national 'Transformation' funding available for cancer alliances that achieve the 85% target. Therefore, breaches can be equated to financial costs for the service, through potentially reduced allocations to the alliance. The exact monetary value for South Tees was not possible to elicit. However, total funding allocated for the Northern Cancer Alliance for 2018/19 was £6,991,000 [NHSE], and the allocation for South Tees would have amounted to a portion of this.

There is good quality evidence that the new roles improved the speed of response and if not for the Macmillan intervention, the number of breaches would have been higher having an impact on Trust's quality targets and potentially leading to reduced funding. The accounts of the interventions that resulted in savings of time on 62-day pathway are stated below:

> “Patient is to be referred to palliative chemotherapy but needs a diagnostic test beforehand however he is currently housebound but needs to have bloods done to allow for this test to go ahead. Phoned the District Nurse and organised for them to visit patient to do the necessary bloods needed.” (Colorectal patient November 2017)

> “Noted patient's pathology results are positive. Phoned MDT tracker and added patient onto MDT for this week to avoid any delay in pathway.” (Lung cancer patient May 2017)

> “Patient is booked in for surgery however needs urgent anaesthetic assessment. Emailed Consultant Anaesthetist to see if happy to have an extra in clinic this week. Informed the daughter of the appointments also bearing in mind she can only attend on Fridays or Mondays so organised this for Friday which helps the daughter out. Saving pathway time, CNS time.” (Lung cancer patient June 2017)

Reduction in the number of non-attendances at appointments (DNAs)

Another system-wide benefit gained by the intervention included preventing appointments being missed (Did Not attend; DNAs). The examples of cases when the DNAs were prevented include cases when CCCs reminded patients of the appointments dates/locations; or accompanied them in the hospital or re-arranged appointments by finding more convenient times. The reliability and validity of these events is supported by being qualitatively recorded by the CCCs in the Intervention Matrix:

> “Phoned patient to inform him of his MRI scan date and colonoscopy date to avoid any DNA. Patient had a couple of queries which I managed to deal with, saving CNS time”

> “Checking patient's bloods have been done and his MRI and CT scans have been appointed. Telephoned patient to inform him that his scans are tomorrow to avoid any DNAs

> “Patient phoned. Discharged 2 weeks ago and not received his review appointment. Checked system and informed patient of his forthcoming appointment. Saving CNS and secretary time. Avoiding a DNA in Consultant clinic”

> “Patient son phoned wanting to know when his mum CT scan is booked for as he is wanting to organise his work load. Checked the system and informed him that scan is tomorrow which he was not aware of. Saving time on pathway and avoiding DNA”

> “Contacted by Mrs [x], her husband has a pre-assessment for a surgical procedure today but had not received a letter to tell them where the appointment would be and were unsure where to attend. Directions given, if I had not done this the patient may have DNA’d their appointment and would have had to wait a further week to be re-appointed.” (Lung cancer, Jan 2017)

Using the unit costs according to the 2017/18 and 2018/19 National Tariff Payment System Annex A, it can be assumed that the cost of one episode of DNA ranges from £71 - £231 depending on the type of appointment as shown in Table 7 below.

Table 7: The cost of DNAs by appointment type

Procedure or item HRG category	Unit cost 2017/18 (£)	Assumptions (if any)
Medical oncology	£214	First appointment to the consultant-led clinic to see single health professional
	£231	First appointment to the clinic involving multiple professionals
	£105	Follow-up appointment to the clinic with a consultant
	£116	Follow-up appointment to with multiple health professionals
MRI scan	£114	MRI of one area, 19 years and over
CT scan	£71	CT scan of one area, 19 years and over
Chemotherapy	£299	Subsequent chemotherapy cycles, assuming that it is not oral treatment
Radiotherapy	£99	Fraction of a treatment of one area of the body

With any new measurement system, there is period of bedding-in before the accuracy of the recorded data can be relied upon. Therefore for the CCC intervention we have used data from January 2017, and estimated that the mean outcomes can be applied across the whole of the intervention period. As shown in Table 8 below, between Jan 2017 and June 2018, 239 DNAs were recorded; however, we were unable to establish the exact type of these missed appointments, e.g. whether these were the first appointments with a consultant or follow-up appointments. For the purposes of this analysis it was therefore assumed that all DNAs to the outpatient clinic were the 'follow-up appointments to see multiple professionals' and therefore were assumed to cost in total £ 27,724 (£116 per individual missed appointment).

Table 8: The number of DNAs recorded between Jan 2017 to Jun 2018

Tumour site	Resource use	Potential cost implications
Colorectal	76	£8816
Prostate	60	£6960
Head & Neck	58	£6728
Lung	29	£3364
Lymphoma	16	£1856
Total	239	£27,724

The available data for actual DNAs from routinely collected hospital-level data was not broken down into the procedure that was not attended (Table 8). However, this information was available from the IM recorded by the CCCs (Table 9).

To estimate the number of DNAs prevented, the qualitative data on the details of each intervention provided by the Macmillan staff between Jan 2017-Jun 2018 was analysed using content analysis. Only the interventions listed as "DNA" or "missed" were taken into account. The number of DNAs, for which the evidence was extracted, that were prevented by the intervention is shown in Table 9 below.

Table 9: Number of CCC and CNS interventions that resulted in preventing DNAs or patients missing appointments

	Number of interventions with the evidence that DNA was prevented*	**Potential cost savings****
Lung	8 [A]	£950
Colorectal	21[B]	£1,870
Prostate	39[C]	£4,469
AOS	6[D]	£1,045
Lymphoma	2[E]	£232
Head & Neck	10[F]	£1,025
Total	86	£9,591

*based on the assumption that the DNAs would not be accommodated within the existing capacity e.g. clinics to overrun or staff staying after hours and that they would cost the equivalent of the national tariff
** All outpatient appointments were assumed to be the follow-up appointments to multiple health professionals
A -included 1 CT scan, 1 lung procedure, 1 chemotherapy, 5 outpatient appointments
B -7 CT scans, 1 colonoscopy, 1MRI, 10 outpatient appointments, 1 diagnostic test, 1 radiology app
C- 33 outpatient appointments, 5 MRI scan, 1 CT scan
D-3 outpatient appointments, 2 chemotherapy, 1 radiotherapy
E-2 appointments
F-3 PET scans, 7 outpatient appointments

The analysis of the data from the Intervention Matrix suggests that 86 DNAs (both first time and follow-up visits or diagnostic tests) were avoided thanks to Macmillan intervention. It should be noted that this finding is likely to be subject to under-reporting, further DNAs were likely to have been prevented, but not recorded.

Using the cost assumptions as in Table 9, the overall estimated cost saving was £9,591 between January 2017 and June 2018. If these savings are assumed to extend across the entire intervention period this would equate to ((£9,591/18)*21) £11,189.50.

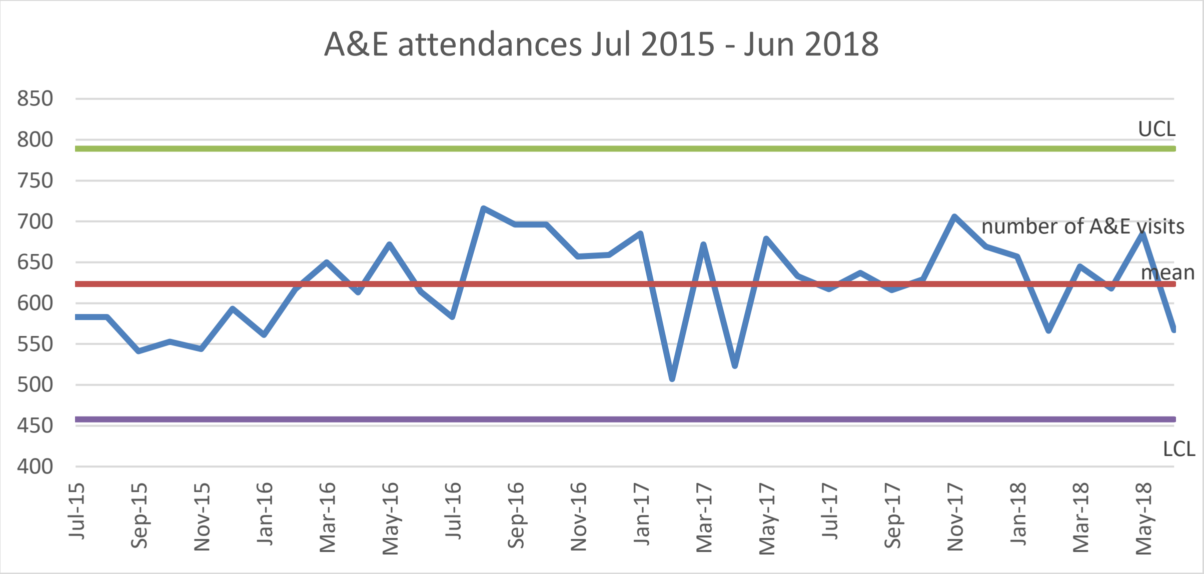
However, this estimate of financial impact on the service has to be treated with caution, as it is a common practise for the clinics to run with extra capacity, where a single missed appointment does not cause any disruptions, delays or most importantly, does not contribute to the loss in the Tariff. It is also worth considering that DNAs could have additional cost implications, more generally across the healthcare system. Current guidance recommends a referral back to the referring clinician (e.g. GP practice) after two consecutive initial DNAs, indicating that additional costs to the whole health care system could be avoided through reduction of DNAs. However, we did not have access to this information.

The impact on A&E attendances

In order to accurately reflect the impact that the Macmillan intervention had on the Trust two possible metrics were considered: A&E attendances between Jul 2015 – Sept 2016 (prior to the intervention) and Oct 2016 – Jun 2018 (post intervention); and hospital admissions for cancer patients. Unfortunately, the routine level data on hospital admissions proved to be too difficult to obtain in the time available due to the coding involved.

The analysis was therefore performed using the A&E attendance data. In order to evaluate the trends related to the number of attendances, especially when the Macmillan intervention was fully implemented (October 2017), the data was first plotted using Statistical Process Control method to identify whether there was any obvious special cause variation, as shown in Figure 8 below.

Figure 8: A&E attendances July 2015 to June 2018



The rules of statistical process control (SPC) chart analysis describe two types of patterns. There are patterns that could either be considered to be common cause variation (caused by expected fluctuations) or special cause variations (expected to be caused by changes in the system that have a potentially discoverable and describable cause) for instance as the result of a systematic quality improvement measure (Western Electric Company, 1956). There are no signals of special cause variation, or any other indicators that there are assignable causes for unexpected situations following the intervention. It is therefore assumed that these variations represent a common variation in A&E attendances. However, caution should be observed regarding the period from July 2015 to January 2016. There are 7 points below the mean value and it is not clear what the pattern was prior to July 2015; if this was also below the mean it would be considered a special cause variation. As it stands, the data for this period could still be considered to represent unusually low A&E attendances, which increase to the highest number (716) in the data series in August 2016 (immediately prior to the intervention).

Whilst the SPC analysis is inconclusive, there is additional evidence to support the relationship between the intervention and changes in A&E attendances and subsequent savings, as the quantitative findings are supported by qualitative investigation, intervention matrix (IM) records and the testing and refinement of programme theories. For instance, the following extract from the IM record indicates a direct relationship, demonstrating how the CCC role can free up time for CNSs to deal appropriately with emergency situations, rather than patients resorting to A&E attendances.

> *Attended clinic with Consultant. Freeing time up for CNS to organise emergency admission/treatment for another patient*

The CCCs frequently carry out activities that enhance patients' practical abilities to self-manage such as coordinating care, offering advice on medication management and diet, and post-operative care.

> *Patient phoned querying his discharge medication. Advice sought from CNS and informed the patient*
>
> *Patient being seen in clinic. I chatted to the wife and she asked for some dietary leaflets to be sent out to help with what he can and cannot eat. Posted out bowel cancer diet leaflets and leaflets from Holistic Centre on their cooking classes*

CCCs are also active in case-findings and ensuring that patients are discussed by the team (rather than being lost in the system) and there are no avoidable delays in their care.

> *After discussion with CNS, came across a cancer diagnosis pathology. Added to MDT and emailed secretary to put patient into clinic to be informed*
>
> *New patient found by checking histology. Added to infoflex and treatment book. Added to MDT for new discussion to avoid any delay.*

A large number of contacts between CCCs and patients and their family members involve psychosocial support, information-giving and signposting to other services to improve abilities to self-manage health conditions.

> *Went to see patient post-surgery on the ward to check she is ok. Daughter present also. Chatted about the operation and what happens next. Psycho/social support... Information giving/sign posting.*

Therefore, there is a wealth of evidence for the effectiveness of CCCs in supporting self-management. As demonstrated in the following extract from a recent report by The Health Foundation, the relationship between patients being supported to better manage their health conditions and less reliance on emergency services is well established.

> "We found that patients who were most able to manage their health conditions had 38% fewer emergency admissions than the patients who were least able to. They also had 32% fewer attendances at A&E, were 32% less likely to attend A&E with a minor condition that could be better treated elsewhere"
>
> (Deeny et al, 2018)

Interrupted time series analysis on A&E attendance data

Interrupted time series (ITS) methods represent a more precise approach than SPC charts to determining the effect of an intervention on a specific outcome of interest. These methods were used to analyse the A&E data for cancer related attendances between Jul 2015 & Jun 2018. It was assumed that the intervention occurred during September 2016, once recruitment and training had taken place. October 2016 is taken as the first data point post-implementation.

Using monthly A&E attendance data for all patients with a primary cancer diagnosis, effects were calculated for 6-months, 12-months and 21-months post-intervention. This approach is sensitive to the incremental changes in outcomes that are often observed as interventions develop and are embedded into routine working practices. The findings from qualitative data analysis support this approach. As the roles of the CCCs and Community Sisters were novel initiatives, which evolved over time to suit the environment that these individuals found themselves operating in.

Before the intervention there was a trend in the slope of an increase of 9.512 attendances every month, which became a negative post-intervention trend of -0.649 (p=0.001). This finding indicates that prior to the intervention there was a month-on-month increase in A&E attendances for all cancer patients. After the implementation of the new roles there was a slight, yet statistically significant month-on-month reduction in attendances. The overall difference between the pre-intervention trend and the post-intervention trend is -10.161 cases per month.

The following findings show an estimate of the difference between the actual A&E data and the forecast of the number of attendances that would have been expected to occur without the intervention at different time periods post-intervention. Note that these do not directly equate with the changes in the overall trend as they relate to specific time points rather than the entire data set. The average per month is given below; note all values demonstrate larger changes at these specific time points than indicated in the overall trend estimate. Also note that the rate of change seems to be reducing over time.

- Six month absolute level effect is a decrease of 93.311 cases (p=0.01; 95% CI=-24.4387 to -162.183). Mean reduction per month=15.55 cases.
- Twelve month absolute level effect is a decrease of 154.276 cases (p=0.002; 95% CI=-60.489 to -248.063). Mean reduction per month=12.86 cases.
- Twenty-one month absolute level effect is a decrease of 245.721 cases (p=0.001; 95% CI= -108.335 to -383.107). Mean reduction per month=11.70 cases.

For all post-intervention time periods there are no positive values in the calculation of confidence intervals, which would strongly indicate that the intervention resulted in a decrease in A&E attendances (i.e. there is a 95% probability that the range of values expressed in the confidence intervals contains the true value). At 21 months post intervention we can say with a very high degree of certainty that these results have not occurred by chance (i.e. less than one in a thousand chance that the results are false).

The trends are illustrated in the graphs below. The vertical blue line denotes the start of the intervention (October 2016). Figure 9 shows the observed number of A&E attendances for all cancer patients. Figure 10 shows the smoothed figures (9-month rolling average) to demonstrate the general trends, whilst leaving out the fine scale monthly variations. Figure 11 shows the pre- and post-intervention trend lines (blue lines) and the forecast trend (red line).

Figure 9: A&E attendances for all cancers pre and post intervention

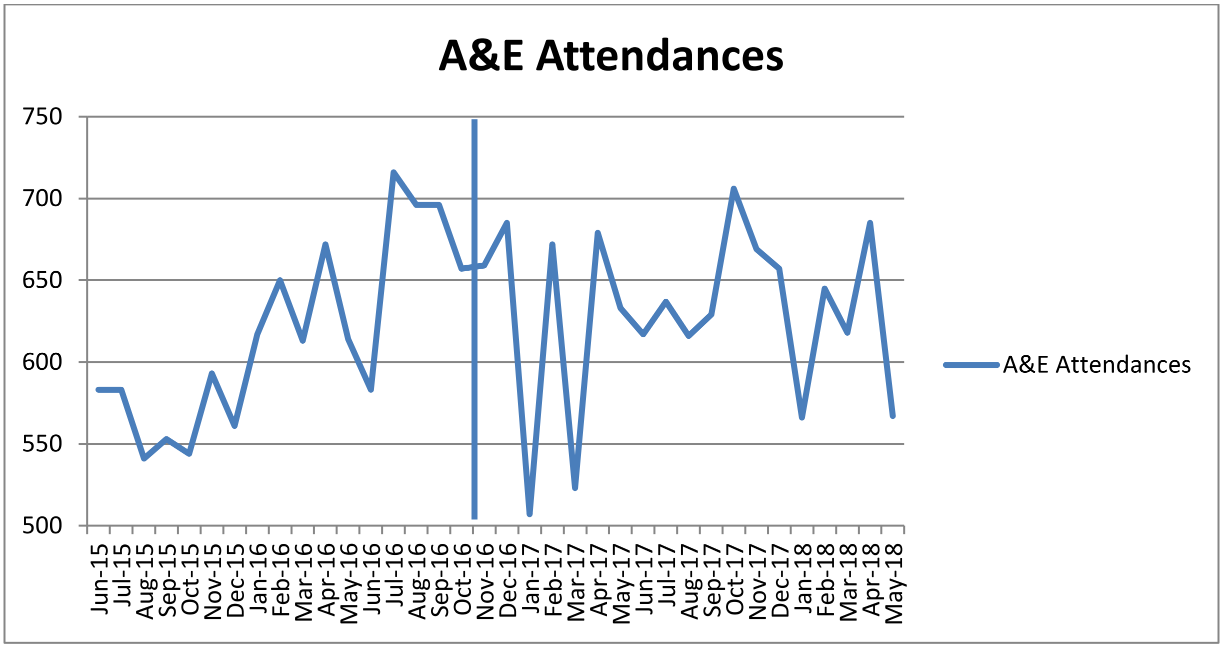


Figure 10: A&E attendances for all cancers 9-month rolling average

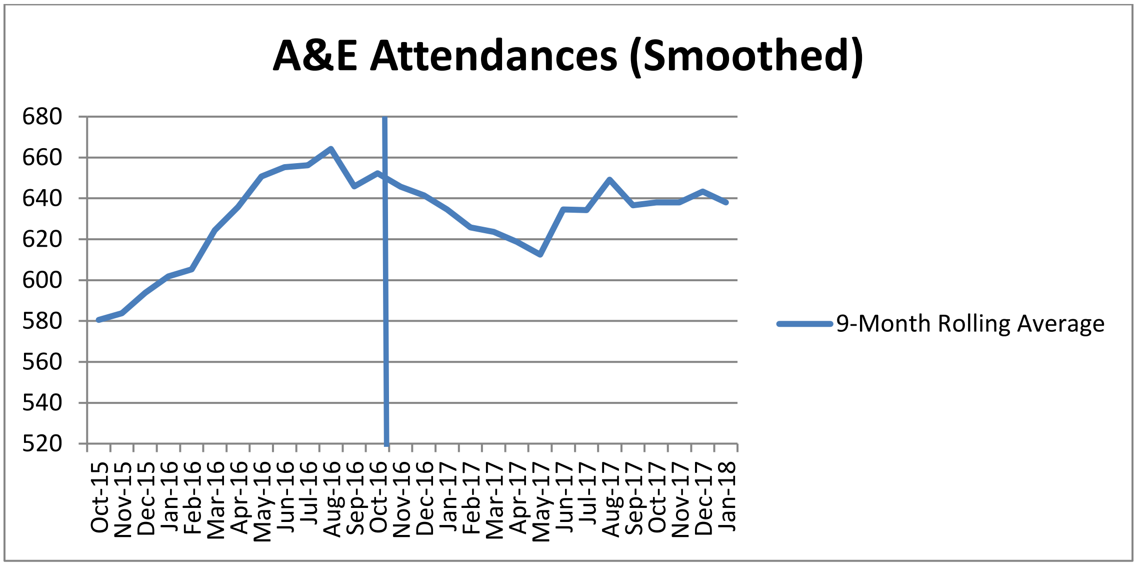
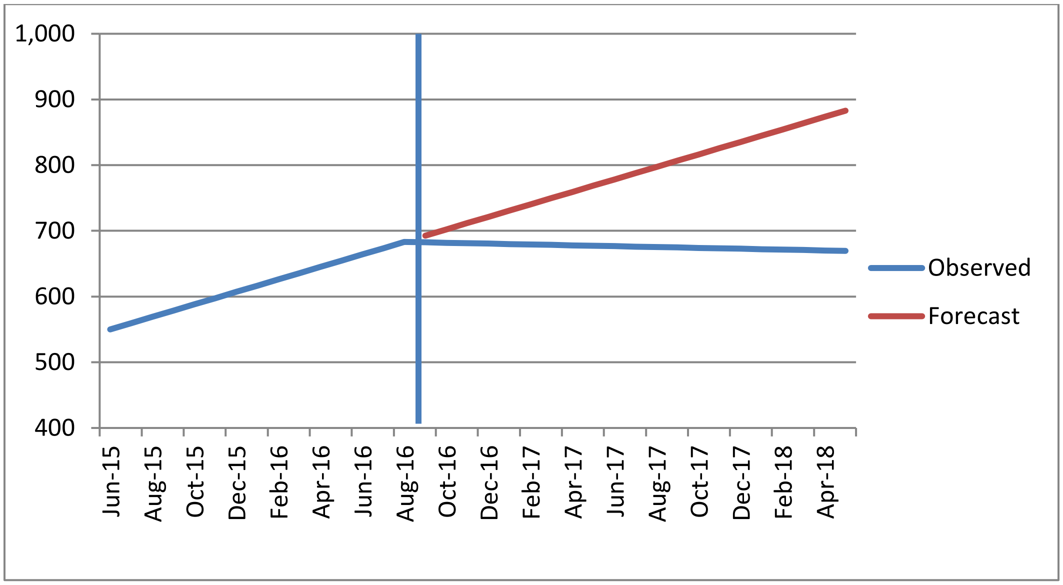
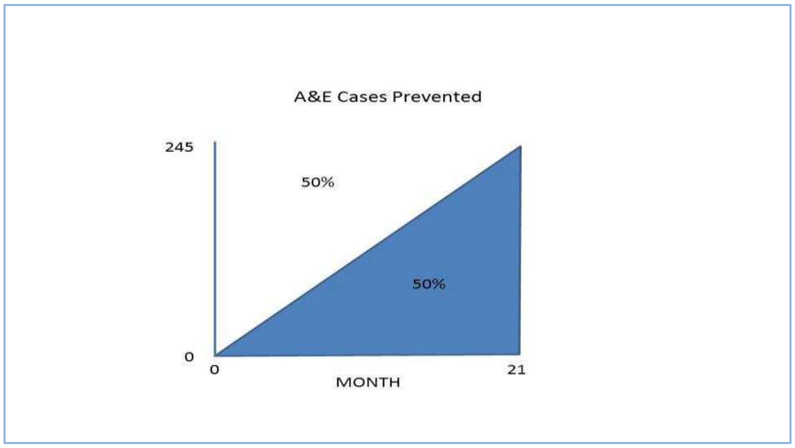


Figure 11: Forecast slope for A&E attendances for all cancers pre and post intervention



As can be seen in Figure 11 as the forecast and the observed data diverge there is an accumulated difference, which represents potential savings. Whilst there is a level effect of 245.721 cases at month-21 after the intervention, this is zero at the time of the intervention (month-0). Therefore, to estimate the impact of the intervention over the period of the evaluation, a simple, linear slope equating to a reduction of 245.721 cases at 21 months and 0 reduced cases at the intervention point was applied (see Figure 12). Assuming a cost of £148 per A&E attendance (Reference Cost Data 2016/17) this could equate to a saving of £381,850.43 ((245.721*21)/2=2,580.071 cases) over the evaluation period. Whilst a slightly more sophisticated model (imputing values, based on the 3 level effect calculations) suggested a higher figure of 2,849.653 cases, both have drawbacks and we decided to proceed with the more conservative estimate of 2,580.071 cases for the ROI calculation.

Figure 12: Diagrammatical representation of A&E cost saving calculation



To estimate potential cost savings to the acute care system, we have considered what impact the observed change might have over a 12-month period. At 21-months post-intervention, the estimated difference between the observed and forecast A&E attendances equated to a reduction of 245.721 cases per month (2948.65 cases per year). Assuming that this difference continues for the following 12-months and a cost of £148 per A&E attendance (Reference Cost Data 2016/17) this could equate to a potential saving of £436,400.50 per year.

It is important to recognise that the magnitude of the observable effect of the intervention is somewhat diluted in the evaluation of changes to A&E attendances, which is for all cancer-related A&E attendances, whilst CCCs where only implemented in 5 cancer specialties. Attendance costs, rather than admission costs, are used for the valuation as we have no information about the nature of admissions or what happened to patients once admitted. Therefore, this is likely to be a considerably conservative estimation of costs. It should also be recognised that the SPC chart demonstrated an increase in A&E attendances immediately prior to the intervention from a long run of months where attendances were below the mean. This could represent an anomaly in the data series, resulting in a steeper forecast trend-line than should be expected and subsequently an overestimate of the effect of the intervention. The model would therefore benefit from more retrospective data.

Non-elective admissions: Whilst not able to explore admissions data, we could assume that the national rates for conversion of an A&E attendance to emergency admissions apply. According to 2017-2018 national data, the average conversion rate is 28.655% of all A&E attendances at major A&E departments resulting in an admission. This would equate to a potential reduction of 844.94 emergency admissions per year (28.655% of 2948.65 cases). Assuming the national average non-elective inpatient cost of £1,590 (Reference Cost Data 2016/17) this represents a possible additional saving of approximately £1.3M/year (£1,343,454.60).

Holistic Needs Assessments (HNAs)

The evidence of other benefits, that were not possible to monetize were also verified. One of which is the increase in the number of Holistic Needs Assessments (HNAs) offered and reducing the time taken for individual appointments due to CCCs involvement. As stated by Project Managers, individual's HNA used to take 2-3 hrs, but thanks to the input from CCCs, who complete all the necessary administration tasks, and collect information during extended conversations with patients, it now takes 20 minutes. Also, they noted that each session is more productive, and patients are able to raise more concerns. From March 2018 HNA is being offered to all patients.

Patient travel costs

Moreover, if we extend the boundaries of the evaluation to include economic benefits for patients, there is evidence that specific patient-related benefits were achieved; specifically including savings on patient travel/time. The data collected as part of Intervention Matrix suggest that between Jan 2017 and Jun 2018, 1010 interventions resulted in savings of patient travel and time. The distinction of whether the patient travel was "saved" was made by the CCCs as part of record keeping (Intervention Matrix) and verified by the CNS. Some examples are shown below.

> "Patient is coming in for surgery and has colorectal pre-assessment booked however patient will also need JCUH general pre-assessment prior to surgery. Organised this for the same day, straight after each other to avoid unnecessary visits to the hospital"

> "Patient is being seen in Guisborough Hospital today. I faxed across his blood results as not available last time to view to save unnecessary Hospital visit"

It is recognised that there is wide variation of travel distances; making the analysis methodologically challenging. Cases were identified which indicated that patients travelling from as far as Hull (return travel distance approximately 200 miles) or the Yorkshire Dales (return travel distance approximately 100 miles) to attend their appointment are common.

The most accurate method to estimate the cost benefits from avoiding unnecessary travels for patients would be by obtaining data on travel mode and distances directly from the patients for whom CCCs intervention deem to have saved the need for travel. The alternative method would be to obtain postcode data for a sample of patients from System One records, in order to make the assumptions for the entire cohort.

Unfortunately, both methods proved to be difficult to achieve within the time available, therefore, it was assumed that all patients were living within the area of 50 miles' radius from the James Cook Hospital; therefore, a return journey to hospital by car would take 2 hours of patient's time.

Table 10. Number of interventions that resulted in travel savings for patients

	Number of interventions	**Potential cost savings***	**Potential time saving (hrs)**
Lymphoma	559	£22,360	1118
Colorectal	143	£5720	286
Lung	101	£4040	202
Prostate	73	£2920	146
Head & Neck	70	£2800	140
AOS	49	£1960	98
CUP	15	£600	30
Total	**1010**	£40,400	2,020 hrs
*The assumption was made that an a visit to hospital would on average cost a patient £40 per return visit by car, and take 2 hrs, but a more accurate estimate would have been achieved if the data on travel distances was available for each case (or a representative mean could be calculated)			

If these estimates are extended to the duration of the intervention then the potential cost savings for patients could be ((£40,400/18)*21=) £47133.33 (and saving approximately 2,500 hours of travel time). However, due to the level of uncertainty and suggestions from the management that there is a lot of variation in the patient travel and time data, the results have to be treated with extreme caution. However, they were deemed important, as they indicate yet another positive aspect of the Macmillan intervention that needs to be explored in more detail.

ROI Summary and Sensitivity Analysis

Non-financial returns

The following is an assessment of the economic impact of the workstream. However, it should also be recognised that this should also be viewed in the context of the benefits to people affected by or living with cancer that are noted in other sections of this report. Individual benefits from patient and family perspectives were not measured as part of this evaluation. However, proxy measures, such as waiting times indicate a positive effect for service-users, and qualitative feedback identified specific ways in which patient and family experiences improved. For instance, the increase in holistic needs analyses and telephone follow-ups to maintain contact with patients and reduce the need for unnecessary visits to hospital are evidenced. Whilst not quantified in this report, these benefits potentially represent significant areas of return for the investment in the new roles.

Financial returns not included

As we do not have direct evidence of reduced admissions following an emergency attendance; changes to non-elective admissions have not been included in the ROI or sensitivity analysis. However, this is potentially the area of greatest fiscal benefit for the health economy; our estimates indicate that approximately £1.3M per year could be saved from reduced admissions as a result of reduced A&E attendances.

Set-up costs

It is reasonable to assume that the implementation and development of these new roles was particularly resource intensive, and a proportion of the 'implementation staff' costs could be regarded as sunk costs, which would not be required to this extent if the roles were spread to other organisations or scaled-up in the current Trust. For the purposes of this evaluation, the break-even point for this pilot programme has been calculated for current staffing levels and includes development and implementation costs. However, an additional cost that has not been included (as specific information was not available) is the time required by CNSs to train and supervise CCCs; particularly as each CCC needs to develop their role to fit into each specific clinical cancer site service.

Return on investment

Using the costs and savings from row F in Table 11 below (i.e. full staff costs for development, implementation and delivery and savings for the healthcare system), the programme provides a £1.05 return for each £1.00 invested over 21 months (£26,768.45). According to these calculations the break-even point (£2,346.64 return) for the South Tees pilot programme occurs in month-13 after implementation (November 2017). If the development and implementation costs are not included (i.e. costs of service-delivery roles only), then the programme has far exceeded the break-even point at 21-months, with a return of £1.12 for every £1.00 invested (£64,107.25).

Sensitivity analysis

The following sensitivity analysis is provided to demonstrate how the inclusion or exclusion of costs and savings affect the final return on investment calculation. It is worth noting that there are important areas of potential economic benefit, which could not be measured or valued in this evaluation; so the returns on investment should be considered to not be representing the full range of benefits. However, there is good evidence for the inclusion of ‘other staff time-savings’, ‘A&E savings’ and ‘DNA savings’. It should also be noted that there is strong qualitative evidence to support the assumption that ‘other staff time-savings’ and ‘DNA savings’ are considerably under-reported. It should also be noted that ‘A&E savings’ for reduced attendances are likely to be under-valued, and these exclude admissions.

As demonstrated in the following table, the ‘A&E savings’ are the area of highest return, which therefore have a considerable effect on the overall level of return and break-even point. However, it is useful to consider that if only the costs of the new roles are considered and areas of saving are restricted to ‘other staff time-savings’ and ‘DNA savings’, which are likely to be considerably conservative estimates, the return on investment is £0.38 for every £1.00 invested over 21 months. When A&E savings are included, this becomes a return of £1.12 for every £1.00 invested over 21 months. These financial proxy returns should also be balanced against the value that service providers, commissioners and service-users and their families place on improved quality of services (e.g. see qualitative evaluation), for instance the improvement in the 62-day pathway compliance.

Table 11: Sensitivity analysis for ROI, at 21-months post-intervention

	Costs		**Savings**				**Return on Investment**	
	Cost of roles	Implementation staff	Other staff time-savings	A&E Savings	DNA savings	Patient travel	ROI Ratio	ROI £
A	£513,170.25	£37,338.80	£184,237.57				0.33	-£366,271.48
B	£513,170.25	£37,338.80	£184,237.57		£11,189.50		0.35	-£355,081.98
C	£513,170.25		£184,237.57				0.36	-£328,932.68
D	£513,170.25		£184,237.57		£11,189.50		0.38	-£317,743.18
E	£513,170.25	£37,338.80	£184,237.57	£381,850.43			1.03	£15,578.95
F	£513,170.25	£37,338.80	£184,237.57	£381,850.43	£11,189.50		1.05	£26,768.45
G	£513,170.25		£184,237.57	£381,850.43			1.10	£52,917.75
H	£513,170.25		£184,237.57	£381,850.43	£11,189.50		1.12	£64,107.25
I	£513,170.25	£37,338.80	£184,237.57	£381,850.43	£11,189.50	£47,133.3	1.13	£73,901.78
J	£513,170.25		£184,237.57	£381,850.43	£11,189.50	£47,133.33	1.22	£111,240.58

Usefulness of the Intervention Matrix (IM)

Introduction to the IM

The intervention Matrix is an information spreadsheet designed to record the activities of the CCC and Community Sister roles. In addition to recording intervention activities, it also records counterfactual evidence for the value of the roles (e.g. saving time for other health service providers).

The following are the headings used in the Intervention Matrix (IM). An example of a 'pick-list' from the reduced IM spread sheet is shown in appendix 3.

Table 12: Headings for the full Intervention Matrix

Date	**Stage of pathway**	**Type of Intervention**	**Level of Intervention**	**Professionals / services involved**	**Time taken for the Intervention to succeed (minutes)**	**Time saved due to the intervention**	**Cost**

Cost x time saved	**Who benefited from the Intervention?**	**Outline (text description)**	**Ongoing Journey**	**Diagnosis**	**Time saved on pathway**

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Table 13: Headings for the reduced Intervention Matrix

Hospital ID	CCG Area	Date	Type of Intervention	Professionals / services involved or saved time for	Time saved (professionals) due to your intervention	Outcome of Intervention

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CCC use of the IM

It was generally appreciated that the IMs cannot give the full picture of what the CCCs role involves. The role is holistic, evolving and innovative which means that the CCCs can spend a great deal of their time with small number of patients with complex needs, providing support, coordination and advice that is difficult to quantify; while the IM only represents the remit of their work and their tasks quantitatively. The variation in numbers of patients seen compared to complexity of patients can also vary by cancer site, making comparisons misleading. However, it should be recognised that there were text fields for short descriptions of activities.

The IM was recognised to take a lot of time to complete, which impacts on the efficiency of the roles. However, it has been recognised as a useful tool to monitor the focus of the role as it developed and to ensure that the role remains well defined and that the CCCs are not starting to carry out tasks that should be covered by other roles. Feedback to the CCCs has helped them to appreciate the value of collecting the information in the IM, for instance when they see that it has saved money for the Trust.

> “The matrix we’ve done for two years, and every slight intervention that we've done from a phone call to seeing someone in the corridor we have to document everything and it was time consuming. We had to put who benefited from our action, was it consultant, was it GP, patient, relative. We had to write what we did, the time it took us, who would have done it if we weren’t there? So this is two years of everything we’ve done from coming to work to going home wasn’t it? It was horrible. But we now appreciate when we've see the final data why it was so necessary because you can’t just make a job up without proving what it’s worth, so we saw the time it saved on the pathway. We've seen the amount of money it saved the Trust.” (CCC focus group)

Community Sister use of the IM

The Community Sisters were involved in evolving the IMs. This evolution resulted in a narrower set of outcomes and was dependent on understanding the development of the role.

> “It's a lot better than it was. We kind of like tweaked it a couple of months ago, in hindsight we should have done it a long time ago. Because it would have been a little bit more easier to read and probably better in the outcome … But we just made it more specific… about the outcome … it could include loads of things but ultimately, in the end, who do we save time for and what was the outcome for that patient. Whether it was save a GP time, avoid hospital transportation, avoid clinic appointments, consultation time, GP practise nurse, community nurse. So it's very specific, if you looked at each patient individually you can look at the outcome and it can tell you what we did basically and how we saved time.” (P1)

> “I think when we first started with the IMs, I mean the IMs another thing that's developed over time and we've switched- swapped and changed what works and what doesn't and I think that IM's always going to be subjective.” (P2)

> “it's a lot quicker now isn't it? It was a full-time job. Yeah [01: Nightmare].” (P2)

The Community Sisters mentioned a lack of feedback about how the IM was being used at senior levels to describe their role. They were uncomfortable about the IM being used for this purpose as they considered it to be an inadequate tool for this purpose.

> “They prepare these reports based around the IM so every three months this report's pull from the IM and apparently this report goes to board. And we sit and wonder what goes on in board meetings [01: We never get invited] and how people are, how people in this board room, how are we being perceived in that board room about what we're doing in community? And we just feel kind of passionate that you know, there needs to be a bit more about what's going on, not just this horrible Excel spreadsheet that we have to fill in every month.” (P2)

Summary of use of the IM

Although the Intervention Matrix (IM) could only capture a fraction of the benefits of the implementation of the roles, it was particularly useful for the evaluation as it provided good quality, validated empirical evidence for the efficiency savings produced by the roles. The short textual descriptions provided strong evidence for constructing hypotheses about the ways in which the roles contributed to more efficient services. These hypotheses supported the quantitative elements of the evaluation by providing rationale for observed changes in key outcomes.

Examination of the quality and type of evidence provided by the IM indicated that it was easier to complete for the CCCs than the Community Sisters. This seemed largely due to the differences between the roles and difficulties in assessing the time-savings for a wide variety of primary, community and acute services.

It should be noted that completion of the IM was considered to be time-consuming and could have significantly reduced the effectiveness of the roles. However, during the early stages of the implementation it is important to understand whether the roles are working effectively. The value of the IM data in demonstrating the benefits of the roles should not be underestimated as without this, much of the evaluation would have relied on assumptions and recollections rather than validated contemporaneous reports. We would therefore recommend the collection and evaluation of the full set of variables and text included in the IM during the early stages of implementation.

The collection of IM data might also have had an influence on the effectiveness of the roles, by promoting self-reflection and accountability for activities. Whilst it could not be assessed within this evaluation, there could therefore be benefits in promoting the collection of IM data for any staff that are new in post. However, in the longer-term it should be possible to reduce the data collection (e.g. remove the need for text descriptions) and/or put in place proxy measures, which would indicate any significant changes in the ways that the roles operate.

Discussion

By exploring multiple data sources, we have been able to identify a wide range of different areas where the Macmillan Cancer Support could have had an impact. However, while we consider the analyses conducted to be the most robust possible given the available data, there are numerous limitations with this analysis which limit the ability to draw strong conclusions as to the effectiveness of the Macmillan intervention.

It could be considered a weakness of the evaluation that both roles were implemented simultaneously and therefore it is not possible to completely disaggregate the costs and benefits of each role. However, it was clear from engaging with the post-holders, their colleagues and service-users that there is a complimentary relationship between the roles; particularly regarding flexibly linking holistic community nursing with acute care. It therefore could be argued that it is necessary, or at least advantageous to implement the two roles together to achieve the benefits demonstrated in this report. It is also worth noting that there were not particularly clear-cut pre-post intervention periods. The roles were developmental (particularly the Community Sisters) and benefits were gradually realised as the roles were defined and 'bedded in' to local service provision.

It should be recognised that approximately 7% of total salary costs for the workstream (£37,338.80) were associated with management and administration for implementation and development of these new roles. This factor also has an impact on the business case for these roles to continue in South Tees, as these implementation and development costs would not be required on an ongoing basis. It should also be considered that if the intervention were to be rolled out to other situations, then implementation and development costs would be expected to be significantly reduced, and should be estimated for each new context; as much of the necessary development work has been carried out. It should also be considered that individual organisational overheads and estimated staff travel costs could be added to the salary costs.

Whilst the Intervention Matrix tended to provide data that was reliable and verified, there seemed to be significant difficulties in recording all instances of cost savings and this was time consuming for members of staff, thereby having an impact on their efficiency. Savings in 'other staff-time costs' as a result of the new roles were considered, and these equalled £184,237.57. However, these are considered to be considerably under-estimated. Whilst the evidence for prevented DNAs is recorded in detail, indicating that the data are reliable and valid, converting this into financial benefits for the Trust could not be achieved with great accuracy. However, taking into account the assumptions made, savings from evidenced reductions in DNAs was estimated to be £11,848.

As discussed previously, there is evidence of important system-wide benefits, for example, in relation to the breaches on the 62-day pathway. As presented in Graphs 1-4, the data appear to show improved trends in these metrics, especially in case of prostate and head & neck cancer. However, it was not possible to assess the financial impact of reducing the 62-day pathway breaches for the Trust.

The ITS analysis for all cancer related A&E attendances suggests that there is highly statistically significant evidence that there is a cumulative effect of the intervention, preventing the upward trend and resulting in a month-on-month reduction in A&E attendances. At 21 months post intervention this resulted in a reduction of approximately 246 cases per month. This equates to a potential saving of £381,850.43 over the evaluation period, which is likely to be a conservative estimate as reference costs for attendances only were used, owing to lack of data regarding the nature of the admissions.

The important areas, that need further exploration, include the impact of the intervention on hospital length of stay and cancer-related hospital attendances. Service-users and their family members were highly appreciative of the service and exercises could also be conducted to assess the value for these stakeholders and apply financial proxies for these benefits.

Conclusion

As the running costs (staff salaries only) are exceeded by the month-on-month returns on investment, and the programme is in a steady-state, it is reasonable to assume that appropriate increased capacity (i.e. providing adequate Community Sisters for the geographical area and expanding CCC roles to all cancer sites) will result in incremental cost savings for the health-care system. Future programmes will also expect a break-even point that is sooner than demonstrated in this pilot programme. The non-financially quantified improvements in quality of care and patient/family experience will also be expected to increase as the roles saturate the system and become better integrated.

The roles were highly valued by the colleagues, service-users and family member consulted. There are clear and justifiable theories for how the roles create improved experiences for people affected by cancer and their families, and how the work experience of other health care professionals is improved. There are notable gaps in service provision that the roles fulfil. There is evidence that the holistic and flexible approaches of the Community Sisters allows PABC and their families to quickly become more resilient, resume a sense of normality and receive advice and support for navigating services.

The Coordinator roles allow clinically trained members of staff to focus on levels of tasks that are more suitable to their experience and training, and improve the speed of services and user experiences. The roles have proved to be innovative, as previous roles linked to poorly coordinated health service processes rather than developing relationships with patients and coordinating service from the perspective of patient experiences. They are continuing to evolve and as such provide a platform for further improvements in cancer care pathways, potential efficiency savings and enhanced experiences of PABC.

Limitations of the evaluation

There are a number of limitations to this evaluation. The qualitative component was limited by difficulties in recruiting adequate numbers of PABC and their family members. Those that were recruited to the focus group had no experience of the Coordinator roles; although they had useful experience of the Community Sisters. Therefore, qualitative evidence for the Coordinator roles was only gathered through members of staff, albeit from a wide variety of roles.

One of the limitations of this evaluation is that it has been restricted to available data sources such as all-cancer-related A&E attendances, and outpatient appointments missed. In order to fully analyse the impact of the Macmillan intervention, patient level data across all of the possible metrics of impact would be required, possibly using the Social Return on Investment (SROI) methods to explore the impact of the intervention from the point of view of all key stakeholders. One of the key outcomes for the programme was clearly service quality improvement, faster treatment and better patient and family experience. However, there were limited data available to quantify these factors and very little opportunity to apply financial proxies to these potential benefits. Therefore, these broader benefits are not represented in the return on investment analysis.

Whilst the access to routinely collected data, and the type of data was particularly useful, and more comprehensive than we would normally expect for a rapid evaluation, there were some issues with completeness and quality. It should also be noted that, owing to data availability, time periods for evidence of benefits and the costs are not always contiguous. This resulted in some extrapolation, which relied on assumptions about the representativeness of the available data over time-periods.

As this is an evaluation of a workstream within an open-system, there could be other causes for some of the recognised benefits, particularly other activities within the Integrated Care Programme. However, through extensive stakeholder engagement, we have endeavoured to uncover any notable activities that might have had an effect on any of the measured outcomes.

To estimate the total cost directly related to the intervention, only the salary costs of staff were considered (e.g. no employer's National Insurance, overheads or travel).

We have made every effort to explore the potential for confounding factors influencing the evaluation findings and to generate and test hypotheses for causal links between the programme and observed outcomes. However, we cannot be certain that changes in outcomes were due solely to the programme. The change in A&E attendances is probably the outcome that could be most susceptible to changes due to external contexts, although we did not find any alternative explanations for the observed findings. However, the difference between observed and forecast A&E attendances could have resulted from unusually low levels returning to expected levels immediately prior to the intervention. To test for this effect, data from earlier before the intervention could be introduced to the model.

Recommendations

Using limited evidence and conservative estimates of benefits, the roles demonstrate significant returns on investment, even when development and set-up costs are included. One of the key areas where the roles could be improved is to make them more widely available, which would also be expected create additional savings and bring forward the break-even point for the pilot programme.

The evidence therefore supports the assumption that the roles offer improved service quality and cost savings, but should be more widely available and stable (e.g. in cases of staff turnover, maternity or sick leave). For future evaluations, we would recommend investigating methods for assessing changes in service-user and family experiences, and if possible estimating proxy financial values for changes.

The Community Sister roles function most effectively when linking primary care, community services, palliative and end of life services and specialist cancer hospital services. Some of the approaches adopted by intermediate care services to maintain communication and effective, appropriate pathways therefore might be usefully applied. It would be useful to monitor referral, signposting and discharge routes on an ongoing basis to recognise and respond to changes.

There appears to be a tension inherent in the CCC roles between maintaining a clear role with well-defined tasks and boundaries as opposed to the natural development of the role within each cancer specialty. Potentially a baseline of core duties, tasks and competencies, which could be enhanced through professional development, could be incorporated into a career development structure for these roles; thereby promoting sustainability of the roles within the healthcare system.

References

APPGC (All Party Parliamentary Group on Cancer). (2017). Progress of the England Cancer Strategy: Delivering outcomes by 2020? [online]. London: Macmillan Cancer Support. [15th January 2019]. Available from https://www.macmillan.org.uk/_images/progress-of-the-england-cancer-strategy-delivering-outcomes-by-2020_tcm9-321006.pdf

Deeny, S. Thorlby, R. Steventon, A. Briefing: Reducing emergency admissions: unlocking the potential of people to better manage their long-term conditions. The Health Foundation. Available from https://www.health.org.uk/sites/default/files/Reducing-Emergency-Admissions-long-term-conditions-briefing.pdf

Hauck, K. Smith, P. Public choice analysis of public health priority setting. In: Cuyer A, ed. Encyclopaedia of health economics. Oxford, UK: Elsevier, 2014:184–93

Pawson, R. Tilley N., 1997 Realistic Evaluation. London: Sage Publications.

Pawson, R. (2013) The Science of Evaluation: A Realist Manifesto. London: Sage Publications.

Manzano, A. (2016) The craft of interviewing in realist evaluation. Evaluation, 22 (3). pp. 342-360.

Oakland, J (2007) Statistical Process Control (6th Ed). Routledge

Neuendorf, K. A., & Kumar, A. (2002). Content analysis. The International Encyclopaedia of Political Communication, 1, 221-30.

NHS England. [no date]. NHS England support and funding for Cancer Alliances [online] NHS England. [Viewed 29 November 2018]. Available from https://www.england.nhs.uk/cancer/improve/cancer-alliances-improving-care-locally/nhs-england-support-and-funding-for-cancer-alliances/

NHSE. (2018) A&E Attendances & Emergency Admission monthly statistics, NHS and independent sector organisations in England (2017-2018, Q1-4). Available from https://www.england.nhs.uk/statistics/statistical-work-areas/ae-waiting-times-and-activity/ae-attendances-and-emergency-admissions-2017-18/

Western Electric Company, (1956). Statistical Quality Control Handbook. Indianapolis, Indiana.

Appendix 1: detailed list of evaluation questions

Evaluation questions

The following guiding questions have been revised and updated during the inception meeting with the evaluation steering group and are based on those originally taken from the evaluation specification.

Key questions

CCC only

- Do these roles offer an integrated, person-centred approach to cancer care for patients?
- What difference have the Macmillan CCC roles made to patient care within their respective teams across the Trust?
- What difference have the Macmillan CCC roles made to individual multi-disciplinary cancer teams they have worked within and wider trust staff?
- What additional nurse/AHP led activity has been developed/delivered due to time savings for CNS and other AHPs? What is the value of this activity?

Both roles

- What have been the economic and cost benefits of the Macmillan CCC and Community Cancer Care Sisters (Macmillan) roles? (Return on investment)
- What have been the challenges and enablers to the development and implementation of the roles? What was the motivation for people applying for the role? To what extent was this motivated by the Macmillan brand/support offer? What has been motivation for staying in the role? How did patients receive them as Macmillan staff (association with palliative care?).
- Is the Intervention Metric developed by the team, fit for purpose in its application to determine the benefit and impact of the Macmillan CCC and Cancer Care Sister (Macmillan) roles? (How might it be improved?)

Additional questions

- What is the perception of CCCs and Community Sisters of their role vs where they started (Job Description)? What has been the evolution of the roles *(Community* Sisters *especially; there are assumptions that the role has changed since the original Job Description.)*
- Do staff understand the nature and purpose of their roles?
- What has been the influence of the programme clinical leadership and CNSs leadership? How have they helped control, shape, develop the roles? How did CNSs respond to their line management role? How has this varied across tumour groups? What is the CCCs experience of their line management?
- What is the relationship between programme clinical leadership and service clinical leadership?
- To what extent has involvement in the programme built relationships with clinical leadership? *(e.g. has the Lead cancer nurse more influence, are relationships with the teams covered by programme different than outside the programme?*)

- Do patients understand the nature and purpose of these roles?
- Do colleagues/partners in palliative care understand the nature and purpose of the Community Sister roles (Macmillan)? *(What has facilitated this - eg Community Sisters sit with community nurses, initially sat with PC)*
- Do Cancer Nurse Specialists in the acute pathways understand the nature and purpose of the Community Sister roles (Macmillan)?
- Is time saved on the 62 day pathways for patients clearly evidenced?
- Is time saved on the pathway for patients clearly evidenced?
- Is time saved for CNSs clearly evidenced?
- Is time saved for GPs clearly evidenced? And other clinical community staff (e.g. community nurses, district nurses, and others)?
- What are the qualitative benefits of time saved for other staff to patients? i.e. what do other staff do with time saved (GPs, Consultants, CNS etc.)?
- What are the benefits to partners (cost and quality) by the introduction of these posts i.e. Social Care, AHPs, District Nurses, Palliative Care Nurses?
- All things considered would patients like to see these posts remain?
- All things considered would partners like to see these posts remain?
- Are these posts fit for purpose?
- How effectively do these roles connect with other services that impact on the journey of a cancer patient i.e. Macmillan Information Centres, Social Care, Community and Voluntary sector organisations?
- Do these roles meet with national strategic direction for cancer?

Appendix 2: Key topics used for development of the programme theory

The following are the key initial themes, resources/mechanisms, outcomes and contexts that contributed to the focus of investigation for the evaluation. The evaluation then sought to develop and investigate relationships between these elements and prioritise the most important and influential theoretical constructs.

Themes

- Integrated services
- Person centred care
- Impact on patients
- Impact on MDTs
- Impact on wider service providers
- Freeing up time and facilitating additional activities for CNSs (& GPs, AHPs etc)
- CONTEXT: Challenges and enablers to the development and implementation of the roles? (What was the motivation for people applying for the role? To what extent was this motivated by the Macmillan brand/support offer? What has been motivation for staying in the role? How did patients receive them as Mac staff (association with palliative care?))?

Mechanisms/Resources

- Role modelling
- Patient advocacy
- Holistic needs assessment
- Pathway navigation (referral and signposting at various stages)
- Promote self-management
- Stratification (esp. for self-mgmt. support)
- Access and interpretation of information
    - aware full range of resources and services available
- Improved documentation
    - patient held treatment summaries
    - care plans
- Providing a single point of contact
- Improve access to interventions (e.g. transfusions, paracentesis, complex pain management and community antibiotic support)
- Vertically integrate primary, community, secondary and social care
- Horizontally integrate the secondary care specialities of Oncology, Haematology and Specialist Palliative Care
- Outreaching services/advice from secondary care (Increasing knowledge in community and primary care
- Flagged for access to step-down care
- Promotion/surveys/workshops
- Post-treatment access to support that might otherwise not be available

- Maintaining patient monitoring systems and records (patient tracking). **For timely patient contact**. Arranging schedule for CNSs to follow up with patients
- Ability for services to engage in quality improvement work as they will have less pressure from administrative burden and patient phone calls
- Attending to psychological support
- Patient centred conversations reducing the need for HNAs or helping to carry out HNAs

Outcomes proximal

- Patients will spend time in hospital only when absolutely necessary (reduced admissions, avoided re-admissions and reduced LOS)
- Increase in self-management
- Care closer to home
- Other quality improvements (e.g. reducing the needs for additional appointments by coordinating visits, increased throughput, producing information materials)
- Impact of the programme on clinical leadership
- Releasing CNS time from administration work and heavy workload

Outcomes distal

- Early referral to palliative care (where appropriate)
- More patients will die in their preferred place of choice
- Reduced cost to the health economy
- Being able to meet policy directives and national and local guidelines (e.g. 31 day and 62 day pathways)
- Increased ratio of planned acute care: Reduced A&E, MAU and AOS
- Improved patient and relative experiences
- Reduce unnecessary burden on primary care

Contexts

Patient contexts

- Extent of illness
- Stage of cancer
- Living situation
- Place of habitation (rural/urban)
- Social support
- Co-morbidity
- Understanding roles of CCCs & CCCSs

CCC individual contexts

- Background/experience
- Clinical knowledge including treatments, side effects, available services and care pathways (and required knowledge)
- Motivation

- Interpersonal style/communication skills
- Caseload
- Length of time in role
- Understanding of role/identity (clinical, admin, coordinating, signposting etc): job evolves over time
- Ability to prioritise care
- Ability to recognise and escalate complex cases & to judge when to refer, and to whom
- Ability to work across organisations and disciplines
- Ability to work independently

CCC organisational contexts

- Others' perceptions of the CCC roles
- Career development opportunities
- MDT culture and practices
- Incentivising (Short-term contract)
- Workload/caseload
- Management (CNS?) & leadership
- Education/training/assessment of competencies
- Peer support
- Day to day working relationships (with specific disciplines)
- Flexibility of engagement with patients, for instance after treatment for coordinating ongoing support or care
- Inter-organisational working relationships
- Cancer site/type

CCCS Roles

Mechanisms/Resources

- Patient advocacy
- Holistic needs assessment
- Pathway navigation/problem solving
- Continuity of care through treatment pathways
- Vertically integrate primary, community, secondary and social care
- Outreaching services/advice from secondary care (Increasing knowledge in community and primary care
- Working in the community across traditional health care boundaries to facilitate right care, right place, right time, right professional
- Facilitate preferred place of death

Outcomes proximal

- Patients will spend time in hospital only when absolutely necessary (reduced admissions, avoided re-admissions and reduced LOS)

- Increase in self-management
- Improved service-user experience
- Care closer to home
- Other quality improvements (e.g. reducing the needs for additional appointments by coordinating visits)

Outcomes distal

- Early referral to palliative care (where appropriate)
- More patients will die in their preferred place of choice
- Reduced cost to the health economy
- Being able to meet policy directives and national and local guidelines (e.g. 31 day and 62 day pathways)
- Increased ratio of planned acute care: Reduced A&E, MAU and AOS
- Improved patient and relative experiences
- Reduce unnecessary burden on primary care

Contexts

CCCS individual contexts

- Background/experience
- Range of clinical knowledge including treatments, side effects, available services and care pathways (and required knowledge)
- Motivation
- Interpersonal style/communication skills
- Caseload
- Length of time in role
- Understanding of role/identity (Info & advice, assessing wellbeing, training and education, leadership, information management and use, monitoring coordination, gathering feedback etc.)
- Ability to work across organisations and disciplines
- Ability to work independently

CCCS organisational contexts

- Others' perceptions of the CCCS roles (especially palliative care)
- Career development opportunities
- MDT culture and practices
- Incentivising (Short-term contract)
- Workload/caseload
- Management & leadership
- Education/training/assessment of competencies
- Peer support
- Day to day working relationships (with specific disciplines)
- Inter organisational working relationships

Appendix 3: Example Intervention Matrix 'Pick-List' for Community Sisters

The following items were included in the IM for users to choose from for some of the columns.

CCG Area	**Type of Intervention**	**Professionals Saved time for**	**Outcome of Intervention**
South Tees	Initial Visit	Acute CNS	Prevented A&E attendance
Hamb, Rich & Whitby	Holistic Needs Assessment	Community Nurse	Prevented Acute bed admission
	IV /Hickman/ Pick line patency	GP	Prevented Community bed admission
	IM/ sub-cut injections	Community Specialist Palliative Care	Prevented Acute outpatient clinic appointment
	Lymphedema management	Acute Specialist Palliative Care	Prevented GP appointment
	Pressure area care	Hosp Consultant	Prevented Community Nurse visit
	Catheterisation	Oncology	Prevented Double GP appointment
	Symptom management	A&E	Prevented GP Home Visit
	Medication review	AHP	Saved CNS Time (telephone/clinic)
	Facilitating earlier discharge from hospital	Chemotherapy	Prevented a wasted journey for patient transport
	Escalation to HCP	Clinical Pharmacist	Prevented Practice Nurse visit
	Nurse Prescribing	Community Hospital Staff	Improved patient experience
	Bloods / cross matching/ vena puncture	Community Pharmacy	Prevented DNA
	Carer support / signposting	Community Therapies	
	Acting as a patient advocate/ facilitator	Continuing Health Care	
	Connecting colleagues/ information sharing	Equipment services	
	IV Drug administration	Haematology	
	Connecting services	Holistic centre	
	Observations	Hospice	
	Organising appointment	Hospital Dieticians	
	Organising collection of equipment post death	Local Government	

	Organising equipment	Macmillan Information Centre	
	Other	Marie Curie	
	Preferred place of death	Mental health services	
	Process discussions	Other	
	Psychological	Public Health	
	Recovery Package	SALT	
	Safeguarding	Secondary Care Nurse	
	Sampling	Social worker	
	Signposting and Information giving	Treatment other	
	Telephone Consultation	Treatment Radiotherapy	
	Wound Care	Practice Nurse	

Appendix 4: Quotes from qualitative interviews to support findings

Theme 1: Understanding of the CCC role

Participants discussed mainly how the CCC role had a positive impact on different aspects of cancer care in acute as well as in community setting. The tasks and responsibilities involved in the CCC role are dependent on the characteristics of the team they are working with. Hence, the role is unique and is tailored to meet the needs and requirements of particular cancer sites. The CNS participants believed that the role involves a mix of responsibilities including running all the "back of house audits" such as collecting data, answering phone calls and responding to them, triaging the patients including looking into blood tests and collecting data for audits, ensuring audits are up to date, doing the admin work to free time for clinical work, tracking patients and ensuring they are on the correct pathway, and dealing with GPs and other health care professionals.

1.1: An innovative role

> "She is absolutely fantastic ... revolutionised our role so where with the things we were trying to do before so trying to keep an eye on when patient scans were taking place, so we'd find out when the MRI was and we'd make sure that the patient was discussed at the relevant brain and CNS MDT. Then we'd make sure they were fed into the right clinic, she's taken over all of that so that's great. Things like if we're trying to ... ring patients maybe with appointments so people ring up and they want more information about things, they can get [the CCC] to do that. She's been great doing stuff like faxing through relevant medication changes to the GPs she's been really, really good, really excellent." (P4: CNS)

1.2: Unique role specific to their associated team:

(different interpretations of the role by each particular tumour group)

> "I think that each cancer care coordinator role is unique to the team that they're working with. So our cancer care coordinator works with physios and OTs and that's very different from the other cancer care coordinators because they don't have physios and OTs attached to the team and I know... my understanding is from cancer care coordinator who works in the acute oncology service she has very little actual patient contact, but it's amazing for the acute oncology Sisters. Whereas I think there's other cancer care coordinators who maybe have more patient contact. In our team [the CCC] doesn't have a lot of patient contact because it wouldn't be appropriate because when the patients... the patients are so complex that their interactions with us is because they've got a problem or because we're ringing to try to monitor their steroid usage for example and find out what's going on." (P4: CNS)

> "I think it went above and beyond to be fair, basically because it was such a new role it was more sort of like a development for each individual cancer to be fair, cause I think there are, the coordinator, my understanding is the coordinator's role because a specialist nurse role is very different depending on what type of cancer those patients have and I think the coordinator's role

> had to equally be as adaptable depending on what that cancer service needed. … I think all of the coordinators' roles have developed differently." (P8: CNS)

> "The Cancer Care Co-ordinator is so there's a few different ones within the trust and I think their roles do differ slightly depending on the tumour groups they are attached to." (P5: CNS)

> "The cancer care coordinator's role, I think has been interpreted slightly different by each particular tumour group, I think it came with a wide remit and I think they had core skills that they had to achieve, you know, deliver, but then I think they had to add variances depending on which other tumour groups that they came into, so my understanding was that they're very patient facing and we gave them more contact to the patients that weren't all about admin, it was important to differentiate that, cause I think that's what they've been used for in the past; what I wanted the patients to have a friendly face in the clinic and a contact." (P9: CNS)

1.3: A profound and meaningful role

The role uses a holistic and integrated approach to address different aspects of cancer care. Therefore, numbers and figures cannot adequately determine the impact of the role and its benefits. It is challenging to capture the whole picture of managing clinical, psychological and emotional needs of complex cancer patients. For example, head and neck cancer patients are highly complex and you need to spend a great deal of time attending to their needs.

> "The reassurance that [CCC role] gives is immeasurable but I'm not sure how much you can quantify that in a numerical way [referring to IMs] but for a, you know, for the emotional and psychological it's absolutely crucial and it makes such a difference to the patient and the patient's family." (P4: CNS)

1.3 Example

> "You can have your day set out in front of you can't you and you get one phone call which leads you to many another 8 different phone calls and, you know, maybe say, for example, if the patient rings up and they're worried because they haven't got a scan date and so that person sitting at home that's absolutely terrified and they're worried that they've been missed off and they're worried about I missed my scan you know, will something go wrong with my tumour and so for [the CCC] then to be able to make a couple of phone calls, check the hospital computer system, find out when their scan is and then ring the person back and say 'hello, Ms X, I've looked and you've got a scan taking place on the 24th of October and I've made you an appointment to see Professor [xxx] on the 30th of October'." (P4: CNS)

1.4: An evolving role

It is expected that any new role would develop and adapt to the context in which it is operating. However, attempt was made to ensure that the role stays within the remit of Macmillan's intention and the original job description.

> "I think that's partially to do with the individual and about their sort of personal view point and it's also others on the team thinking about recognising things that can be done that you know

> someone else can do so you know I think it's something that can develop and I'm sure it's something that can develop further in future as well." (P5: CNS)
>
> "I mean has it definitely has been [evolved], I think cancer care coordinators' job would all involve a core set of skills that's similar to our job but then we have to add on sort of like bolt on a few like extra skills depending on the needs of the patient and the direction that the pathway goes but those extra skills have to be you know, obviously we're responsible for our delegations as qualified staff so, … if we did want her to do something different to cancer care coordinators we did, we got approval for that, and put her though the approved training as well." (P9: CNS).

1.5: A holistic role

The coordinator will be involved from the diagnosis where patients are given contact details and are introduced to the service. The coordinator will follow their investigation journey and will put them on MDT at the appropriate time. Patients will be identified if they need additional information such as travel information or psychological support. The coordinator will do a telephone follow up to make sure how the patients are coping with the side effects of therapies and will guide them with symptom management.

> "I feel sort of like the when they came into call, it helped sort of our Specialist Nurse role to be more sort of geared towards actually dealing with the more complex issues with patients, you know, and having time to do that as well because a coordinator was there to sort of help with sort of like some of the administration not a lot of it (mmm) but sort of like to support us with, you know, identifying issues with patients when they were doing sort of telephone reviews and things like that as well. … they could then sort of like channel patients to right services … she [the CCC] set up the support groups again and which we weren't able to do to be honest, to be fair, you know beforehand, cause there just wasn't the time to do it, basically. So, there's lots, sort of like a lot more things being able to be developed within the service so that we could do sort of like a full holistic service for the patient really." (P8: CNS)
>
> "The new roles are to help the patients journey through the pathways as smooth as possible, to complete the holistic needs assessment and to be patient support when the patients are going through that journey and to sign post to other departments and services outside of the hospital and to help with finance matters. … she's been a great help, helping them with, if their struggling financially, help the carers, you know the families as well, signposting them to carers groups. So she's integrated really well within the team and patients look to her as a first port of call, rather than to me." (P2: CNS)
>
> "I see that as the main role for the Care Co-ordinator in terms of providing a seamless pathway or enhancing the pathway of care for the patients and also for improving survivorship issues long term." (P15: Neuro-oncology physiotherapist)

1.6: A clinical role

> "The care coordinator for lung cancer, we put her through a course, where she become AITP registered for a spirometry for performing the care, so she would be the first meet of the patient in clinic and assess the patients, see if they're suitable for her to do a breathing test, which gave

> us a lot of information; so she would do that faithly, and she knew when to ask you know, us to intervene cause she the patient you know, wasn't suitable to do it. So that was a unique role for her actually, she'd know the cancer care coordinator did that but because it was such a large part of our role each test can take 20 minutes and the specialist nurse would do that prior to being see by the consultant, so that saved us that time every time she did it in clinic so that's an awful lot of time for us saved, and she also then built a sort of relationship with the patient as well so when they were phoning the phoning, they knew her name." (P9: CNS)

1.7: Macmillan branded role

People's perception of Macmillan (and palliative care) is that the organisation is linked to end of life care. It was suggested that rebranding and changing the name could facilitate the way people understand the services and how they might approach them. There were instances where patients were extremely upset and confused to see a Macmillan coordinator when they came to see the results of their diagnosis and the coordinator had to hide their badge or explain to them that they work with all kinds of tumours both malignant and benign.

> "In terms of the branding of Macmillan, we have real difficulties referring patients to Macmillan. We know as health professionals that it's very different and Macmillan provide – you know, a range of very good services not just end of life, but patients don't know that, and even when we try to explain, you know, often they don't want to access those services just because of the name. We have the same problem with palliative – the term palliative services as well. Patients don't necessarily want to access palliative services because they see it very much as end of life, and it can be a real, real barrier to accessing services, you know, trying to really sort of convince somebody that actually it's not all about end of life, it's about support throughout any part of their journey. But you know I understand things are changing and people 's perceptions are changing and I think it's probably the older generation that struggle a little bit more than the younger generation with it." (P15: Neuro-oncology physiotherapist)

Theme 2: Understanding of the Community Sister role

It is assumed that the Community Sisters roles are fit between palliative care, district nurse services and hospital when the patient group don't have complex clinical needs. The Community Sisters can support patients who still need support with the nurse specialist in the hospital and don't come under the remit of specialist palliative care. Although the majority of the participants believed that the role supports patients with their emotional and psychological needs in the community, the Community Sisters carry out some clinical works in the community with patients with less complex needs. The Community Sisters are open to further training to improve their competencies in order to take on more clinical responsibilities but due to the cross boundary nature of the role they are likely to work with different types of cancer and learn more skills over time. The role provides them with opportunities to work with the site-specific clinical nurse specialists and seek advice from them while at the same time the clinical nurse specialists can learn a different skill set from them around how to support people at home and in the community through a mutual development process.

2.1: bridges the gap between the specialist palliative care and the cancer nurse specialist for non-complex patients

> “My understanding is that there are some patients that don’t come under the remiss of the specialist palliative care team, but they could still do with more support than just the support given by the specialist... the nurse specialist in the hospital and that’s where the cancer care Sisters would be able to support the patient group. Have to say that, unfortunately, because our patient group is so complex, we haven’t been able to use the cancer care Sisters because the patient group is too complex for that role.” (P4: CNS)
>
> “And my understanding is, it’s patients who don’t need to direct support from the clinical nurse specialists in the hospital, but don’t necessarily need specialist palliative care support as well.” (P5: CNS)
>
> “Those are nurses who work with patients who are either going through the diagnosis or are perhaps newly diagnosed or undergoing treatment to provide that additional support in primary care, which has always been a bit of a gap – a bit of a grey area – because obviously there are site-specific special nurses working in the hospital and then you’ve got specialist palliative care, but obviously there’s that big gap in the middle and that – those were the patients that generally – that the Community Sisters pick up – I know that they also do work around enabling people to get back on with their lives once they’ve completed treatment and keep a bit of a watching brief on people for a while, and obviously patients that are palliative; they can continue to support until they need specialist palliative care input”. (P13: Palliative specialist nurse)
>
> “There was a gap identified between the specialist nurses in the hospital and patients needed palliative care that there was a gap for support recognised particularly some tumour groups but generally and that these posts were trying to look at additional support for patients in the community above and beyond what their tumour specific were offering … supporting the patients through the diagnostic pathway and treatment pathways with appointments and those kind of things and with and as the role if they’re having treatment they all have the chemo line but just to additional support on top of that as well with any symptoms or anything like that”. (P14: Palliative specialist nurse)

2.1 Example:

> “I did reach for one gentleman but it very quickly became apparent early on that... it wasn’t going to work. He needed clinical expertise and support from myself and from the palliative care team. So, I think it‘s a fantastic role and I think that there are some patient groups like maybe ladies with breast cancers, colo-rectal patients who sort of don’t need the clinical expertise of their CNS but do need more emotional support in the community and they’re not at palliative care stage. I think it’s a fantastic role for them but, unfortunately, in my patient group, the role doesn’t fit.” (P4: CNS)

2.2: More focused on emotional and psychological support in the community

> “They’re there to sort of like help us to support our patients either while, you know, going through treatment or when they’ve just completed treatment, both physically, you know, with

sort of like symptom management a lot to do with the psychological support as well, cause Head and Neck cancer patients … it’s pretty complex, we have a lot of sort of background social issues, and things like that as well, you know, so our cancer Community Sisters have been sort of like superb in helping us with our complex patients.” (P8: CNS)

“When our patients leave us they feel a little bit bereft really I suppose, that lifeline has been umbilical cord has cut you know, you’ve had all your treatment, you go sort of thing and you’ll be well it’s irregular you have to be fair, but sometimes just as that extra bit of help in the community and then a lot of the help is just reassurance and support (also psychological support); mostly psychological support.” (P9: CNS)

“I think, the patients I’ve referred, its mainly been for psychological support and sometimes, mostly for the patient, but sometimes the patients’ family as well so it’s mainly for people who are having difficulty coping with the diagnosis of cancer or coping with the progression of their cancer and then requiring more support and intervention because their cancer is progressing. So they then might need involvement from the district nurses or OT’s or wherever.” (P7: CNS)

2.3: A new role in the community

“It gives us a bit more reassurance that our patients are still being supported in some way, you know, sort of through the treatment because district nurses and community Macmillan their roles are completely different, you know, they can’t pop in to sort of like say that these patients are doing OK mentally, you know, the Mac district nurses are there more for sort of like the physical aspects of things rather than sort of like the mental health, whereas our community cancer Sisters have been, you know, instrumental in sort of supporting our patients through sort of like the psychological side of things.” (P8: CNS)

“Especially in a new post its got to be flexible because you know often you can see there are other things that are more important and or somethings are not relative it’s very difficult in a new post the job description would have to be an evolving thing and reviewed and looked at so that you know we’re making sure that you know the service is designed around the patient need.” (P14: Palliative specialist nurse)

2.4: Supporting clinical needs in the community

“They do do hands-on care so, they do take bloods and my understanding is that they can flush the lines and whatever else really a patient needs. So, they work - they sort of bridge of the gap between a clinical nurse specialist and probably do some of the roles that might have been traditionally under the domains of the district nurse.” (P13: Palliative specialist nurse)

“…by clinical I’m thinking about symptom support type things so yeah clinical as well some clinical”. (P14: Palliative specialist nurse)

Theme 3: Others perception of the roles

Originally there was confusion between the Community Sister role and district and palliative specialist roles. However, the Community Sisters do not have the particular skills for terminal and end of life patients referred to them by the CNSs and therefore this would be challenging to respond to the referrals from the hospitals. The CCCs role is confused with admin role, MDT role and nursing role. The role needs a strong management to describe the role in detail and inform health professionals including nursing staff, consultants and admin staff about what their expectations of the role should be.

3.1: Confusion about the Community Sister role

> "When the Sisters came first so I think people wondered where they would fit and I think it was maybe more the hospital team wondered where they would fit I think that the district nurses understood quite clearly where they were gonna fit. I think there was some concerns, maybe, as to where they would fit between palliative care services, district nurse services and hospital. But, I think, that's been well, you know, sort of articulated now." (P4: CNS)

> "I think initially people like GP and patients sort of didn't really know where that role fitted it and sometimes there were referrals to that service and weren't appropriate because really they were palliative care or really they were something else I mean not unaccepted when the service is new and I think initially my experience was that GPs referred to the service for different reasons sometimes appropriately and sometimes not." (P14: Palliative specialist nurse)

3.1.1: Crossing role boundaries

> "I think the risk was that the community specialist palliative care staff felt that they were taking over their job and I think the that clarification had to be made quite clear that these can't take on patients that are terminal, end of life palliative cause see, there wasn't enough of them, but two they don't have that subset of skills could, so it was you know, each specialist any specialist nurse could refer on to them, and I think we've got busier and busier and busier as you know, like any service starts our small, as word gets out that the you know, it's quite helpful it's grown." (P9: CNS)

3.2: Some early work required to define the CCC roles

3.2.1: Mixing up with MDT role

> "The cancer care coordinator role was very new, I think, people did wonder what the role was gonna be about and, I think, that occasionally people still got mixed up between the MDT coordinator role which is very much about tracking patients through the system and doing all of the, you know, the 65 day target, things like that, 31 and 65 day target so, I think, occasionally people got mixed up as to who does what but I think otherwise is quite clear." (P4: CNS)

3.2.2: Mixing up with admin role

> "She comes from a secretarial background and she knows how to do these things and they're aware that she knows how to do certain things like book appointments and things. But the people

who are managing the co-ordinators have been very active in saying ‘no this is their role, they are not there to be a secretary or a clerical person’. So, they’ve kept a quite tight hold on that but I think from other people’s perspective, not clinical, but from an admin point of view, people have said to me ‘well why can’t she do that, and why can’t she do that it would make life easier for me’. And they haven’t quite understood her role.” (P7: CNS)

“I think it takes quite a strong manager to stop that and say ‘No, that’s not her job, you need to put that to your secretaries you know.” (P9: CNS)

3.2.3: Mixing up with a nurse role

“The risk is as well that the consultants think she can do the same as a registered nurse, and it’s the cancer care coordinator has to be quite you know, be able to you know, often a band 4 will challenge a consultant but if she you know, the cancer care coordinator has to say ‘Actually, I’m not allowed to do that and you need to speak to my manager or the other specialist nurses, and yeah, so I think that my that are more than anything really, because I think they’re just seen somehow as a consultant to see the nurse anybody pair of hands.” (P9: CNS)

3.3: Competency with Community Sister role

3.3.1: Having broad skills

They’ve got a very broad range to cover and I don’t think you could have, could have done sort of being trained up in a specific tumour group because it wouldn’t, it wouldn’t be, you’d have to work in that area for a long period of time to get that knowledge and skills in that particular area if you know what I mean. So I think that in the roles they’re in, I don’t think they could be specialist in each area I think it’s more the broader skills I think that they would need really to do that.” (P.5: CNS)

3.3.2: Obtaining cross-boundaries skills by experience rather than having more training

“I guess if you’re working as a clinical nurse specialist in one type of cancer then it is easier to build up that expert knowledge around that cancer but if you’re actually covering lots of different cancers then it’s going to take a little bit longer, if that makes sense. But still, I would see that there would be opportunities for that sort of cross boundary working, it’s a bit like what we do in palliative care we see every type of cancer and every type of palliative patient, so if we don’t know, we would go and ask and find somebody who could help us, so I’m not sure that that should be a huge barrier or a problem, but certainly that’s not been my experience of the nurse that we’ve worked with.” (P13: Palliative specialist nurse)

3.3.3: Mutual and two way process of learning with CNSs

“I think they can, but obviously, like any nurse, if there’s anything that you’re not sure about you would always seek that advice and I would say that that advice could then come from the site-specific clinical nurse specialists. And there should be that flow of information and support both ways because, in effect the community nurse will have a different skill set and that’s really around how you support people at home and they can – I guess – support the site specific nurses in

> understanding what the challenges that the patients are facing at home, so it’s a two way process.” (P13: Palliative specialist nurse)

Theme 4: Challenges and enablers to the development and implementation of the roles

The main challenges facing both roles are others’ understanding of the role including health professionals and patients’ perceptions of the roles.

4.1: CCC role

4.1.1: Initial challenges

> “I think the initial challenges when it first came... because it was a need post there was lots of... there were anxieties about what they would be doing and, I think, initially people were unsure as to what they would be doing.” (P4: CNS)

4.1.2: Ongoing challenges

> “I think the biggest problem in maintaining them will be down to financial, you know, whether or not they can be funded.” (P4: CNS)

4.2: Community Sister role

4.2.1: Apprehension and resistance to the role

> “The main challenges and barriers I think with any new post, it - professionals understanding what that role will involve, and I think sometimes professionals become quite – or can become quite resistant and quite challenging to new people coming in because they fear that they’re going to be taking some element of their role but certainly in – in our case I would – that has not been an issue because certainly can see the benefit of having that person who bridges the gap, who – who’s definitely fulfilling some patients’ unmet needs where traditionally we’ve found it quite hard because we’ve not been able to provide that service that she had.” (P13: Palliative specialist nurse)

> “I think some of it was the logistics and the start up because when the Sister started here she didn’t have an office, she didn’t have a phone line, she didn’t have the infrastructure ready when she started so that was quite difficult and to that you know it was a time limited project and that took a chunk of the time for her to you know get her referral pathways and communication methods going so I think that was quite difficult.” (P14: Palliative specialist nurse)

Theme 5: Understanding of the Intervention Matrix (IMs)

The IMs cannot give the full picture of what the CCCs role involves. The role is holistic, evolving and innovative which means that the CCCs spend a great deal of their time with small number of patients with complex needs while the IMs only represent the remit of their work and their tasks quantitatively.

5.1: Linking limitations of IMs to the holistic nature of CCC role

> "It's very time consuming and it's very time consuming for the specialist nurses to check and verify but I understand that, you know, you have to some way of recording how useful an intervention is … I suppose the metric is fantastic in that it captures some information but I don't think it gives a total picture." (P4: CNS)

Theme 5: Example

> "Yeah it's a bit like you know when I worked as a district nurse people could say to you how many visits have you got and you could say I've got 30 visits today, you might have 30 visits but it might just be 30 injections which really, you know, you're in and out you could have 2 visits with highly complex, emotionally charged situations and be far more draining, but in terms of numerical value, you know you can't measure it, can you?" (P4: CNS)

> "If you compare the numbers we have with our patients with tumour groups such as the breast team, colorectal team, lung teams, we have much much less numbers of patients coming through but as I said our patients are highly complex and I think as nurse we sort of feel very often it's difficult for us to sort of say you know we've got much less numbers than maybe the other tumour groups have but it's sort of complexity that takes up a lot of our time really. I think that's exactly the same for the co-ordinators in such you know we do have much less numbers but with lots of complexity so that does take up a lot of time. So, it's very difficult to measure that really." (P5: CNS)

> "I think it was probably helpful in the in the first off, you know, to identify how sort of like the service developed, and but actually for them to continue to fill it in, I'm not really sure. … I would hate to think that they'd have to fill that in on a day to day basis, right through sort of like their you know, the their job role, you know, it's but I think it's served a purpose definitely but I think it was a little bit mundane, a long-winded and it didn't sort of like identify fully, you know, what was, what the service offered really. … it is sort of like a number crunching thing really, isn't it? But because it's a holistic thing you can, you can't always put that down on a sheet." (P8: CNS)

5.2: Linking IMs to the original job description

> "I think it's pretty much what both she and I expected of the role. I mean obviously there has been a significant increase in referrals for prostate cancer this year, and all of our roles do develop and adapt, but we've been very careful to make sure that her, her work and what she does is very much in keeping with what the remit of what Macmillan wanted. They've been very involved in, they've got regular meetings with the cancer care co-ordinators and they've done an evaluation and they've completed a matrix [IMs] about what they're doing. And, occasionally they might have said to me 'I think she's doing a little bit too much admin', you know things that the secretaries should be doing, so they've kept I think, her role very tight in keeping with the original job description." (P7: CNS)

5.3: Linking IMs to the effectiveness and impact of the role

> "I don't think it truly reflects the work that the girls have been doing here in the hospital, we've been trying to get them a permanent position and I don't think that really reflects, it's just a series

> of graphs, there's nothing to say yes the girls have saved this amount, yes they've saved this amount of time. But it's not clarifying then what that time, what's been done with that time, that's basically what the trust want you know. Trusts want to know, what, how has that time that's been saved been utilised." (P2: CNS)

Theme 6: Perceived patient understanding of the roles

Although patients might not identify professionals in different uniforms but the impact of the role on patient care has been recognised by them.

6.1: CCC role

6.1.1: General perception

> "I think the patients were just as equally quite happy to speak to somebody you know, who was who was non-nursing about issues that they had as well." (P8: CNS)

> "They're sort of very happy with things, we sort of explain what the role is and everything and they're more than happy to speak to the co-ordinator when we're not there. And the co-ordinator is very clear when each patient she needs to speak to and when it needs to be relayed to a specialist nurse so we are very aware of the boundaries. And so if a patient needs to specifically talk to us its fine they can absolutely do that but when it's about doing the more simple side of things, then it absolutely can be a care co-ordinator. And a co-ordinators' got the skills needed to deal with patients very effectively and sensitively." (P5: CNS)

> "When they first meet people in the outpatient clinic, when they first are diagnosed, or even after diagnosis, that's obviously a very stressful time for most patients and their families. And, I don't always feel that they appreciate the different roles, they just see someone in a uniform and think they are either a doctor or a nurse. So I don't think from the very beginning they necessarily understand the role, they just meet somebody who's going to help them. … The patients are very accepting and I think that they are obviously, most patients are very happy when somebody answers the phone to them and you know, if I was out of the office and patients were leaving messages, that can be very frustrating for patients. So to have someone who is there and answering the phone and possibly dealing with their queries straight away is a big bonus for patients." (P7: CNS)

> "The patients really love that and they're so grateful for you know, [the CCC] can do all the phone calls to say you know, 'you were in clinic last week, did you understand everything that we've said' and 'how're you doing' and 'anything else we can get for you', and such, so they feel very supported and I think the service that we're very lucky to have really and I think you know, to an, when as we know, like any NHS services we're not fullish with staff and it just gives us a bit of time to have that, the soft stuff, in contact and the reassurance." (P9: CNS)

6.1.2: Confusion about the role with benign tumours

> "Our patients obviously do have a lot of support from us with benign tumours and I think sometimes it's a bit tricky because obviously their role is a Cancer Co-ordinator and the name

> cancer in front of that makes it very difficult with the patients because maybe understand how they are supporting, you know, the benign tumours support in their role. So that does make it a bit tricky in terms of how we introduce the Cancer Care Co-ordinators to the benign tumours because obviously that would be a very alarming to the patient if you start to introduce the word cancer when they haven't got cancer." (P15: Neuro-oncology Neuro-oncology physiotherapist)

6.2: Community Sister role

6.2.1: Community Sister role within a home environment

> "We get an idea about sort of patients home circumstances, you know, when we when we meet them and things like that but actually, you know, those these Community Sisters going out to see them, can sort of identify a little bit more, I think sometimes it's easier for patients to open up in their own environments, you know, rather than in a hospital environment about issues that might be going on, so they, you know, they do see additional things that you probably might not be identified, within a hospital based setting." (P8: CNS)

6.2.2: Introducing the palliative care gradually to patients

> "Sometimes patients are very apprehensive about palliative care involvement and so in some ways it can work well in that the nurse can facilitate that introduction, if that makes sense. Or in other situations, if the patients really just don't want palliative care then we've been able to support the nurse to be able to provide some of that palliative care that that patient might need." (P13: Palliative specialist nurse)

> "I would say very positively, because it's somebody who can support them in their own home, it's a scary time when someone is newly diagnosed with cancer and people are thrown into a sort of a world of new things that they've never experienced before so - very positively because it's somebody who can support them through that journey and that pathway." (P13: Palliative specialist nurse)

6.2.3: Confusion about the role

> "I think some of the patients just thought it was a bit of befriending service which clearly it's not and then other patients really you know realised that the value of having that extra support in addition to the tumour specific nurse some mixed, mixed I think." (P14: Palliative specialist nurse)

Theme 7: Impact on time savings for staff or impact on quality of care

7.1: CCC role

7.1.1: Positive impact on time savings

> "Absolutely yeah and I can completely 100% see that it definitely did cause we actually, the CCC has left cause it was a pilot and not a, it was a temporary contract and she just recently left in the last three months to a permanent role and we haven't had our coordinator replaced; and the significant impact that it's had on our service again for our specialist nurses, it's just it's just escalated our workload unbelievably." (P8: CNS)

> "They're there to help support us to do our job to free up some time so we can spend more direct time with the patient. … I think there's some quality, to the, to the role there because of the things that we can't necessarily find time to do, that the Cancer Care Co-ordinator can help so that patients, for example, aren't waiting for long periods of time for an appointment. And they can have the patient ring up and know when their appointment is instead of waiting for a letter to come through, and things like that." (P.5: CNS)

7.1.2: CCC had no time savings impact but improved quality of care

> "Well we've had quite a few discussions about this actually, and what I've explained to other people is that in real terms probably no, because we've had an influx of referrals so my workload has actually increased dramatically. So, because I've got more work to do I haven't got any less time because I've got a cancer care co-ordinator working with me. But obviously I wouldn't have been able to cope so easily in my role, with the influx in referrals if I didn't have her to do a lot of the things that I would have had to do. So she's definitely helped but I can't say she's saved any time because our workload has increased significantly." (P7: CNS)

7.3: Community Sister role

7.3.1: Community Sister had no time savings impact but improved quality of care

> "I'd find it hard to say that it has. I think that it's improved the quality of care, but that would be the main thing." (P13: Palliative specialist nurse)

Theme 8: Connection with other services

8.1 CCC role

> "The CCC used to sort of like regularly refer patients, you know, for benefits, advice you know, equally, she would refer to our, we've got a holistic centre as well, you know that provides complementary therapy, she would also sort of like connect up to, she'd even do sort like clinical psychology referrals, if we identified that they needed additional help, that way as well, so she would do a lot of our referrals and equally sort of she would pick up sort of like our paperwork side of things so that we could continue to see these patients, rather than having to write everything up as well she would do a lot of that for us as well." (P8: CNS)

> "Obviously when the cancer care co-ordinators first came into post they were given a six week training programme and part of that involved a lot of, education and training about other support services that you've just mentioned. So, you know, dieticians, occupational therapists, neuro-oncology physiotherapists, the Macmillan Cancer Centre. So that was very much part of their initial training. And that's very obvious when they came into post that that was very much at the forefront of their mind about referring patients to the Macmillan Cancer Centre." (P7: CNS)

8.2: Community Sister role connection with district nurses

> "These are often patients that the district nurses wouldn't be involved with because there's no nursing needs so you know they might go to see a patient and identify that there is some extra

> support needs but not be able to able to fulfil themselves cos of their referral criteria so I think good for them to be able to have someone else to refer onto to get that patient some extra support." (P14: Palliative specialist nurse)

Theme 9: Impact on quality of care; leading to long term impact on quality of life, improved health and well-being, reduced hospital admission and reduced GP attendance

The impact of the roles has been significant on improving quality of care which would lead to improved health and well-being, reduced hospital admission and reduced GP attendance.

9.1: CCC role

> "As the specialist nurse we, we now do a nurse-delivered meningioma clinic that it wouldn't have been possible to do before [CCC role]. So, that's freed up some consultant time because it's sort of a nurse-delivered clinic so it's definitely freed up some time. And with the allied health professionals, part of what our co-ordinator does is organising equipment and things, so that's again, it's freeing up their time to do other things. … So in terms of that pathway it doesn't necessarily make a difference but in terms of the patient's pathway and certainly of their quality of life it certainly improves things. So it certainly helps to co-ordinate things and making sure the patients get scans and appointments in a timely way, get discussed in a timely way at our MDT meetings so the pathway's certainly been enhanced from that side of things." (P5: CNS)

> "Definitely, yeah, I mean, you know, before she came into post, our opportunities to actually sit and have a couple of telephone calls that they sometimes last half an hour an hour, we couldn't do it we've couldn't, we didn't have the capacity for it, but she can make pre-emptive pro-active phone calls and, and I think sometimes that can stop the patient from worrying so much and possibly bouncing back into hospital." (P9: CNS)

> "[The CCC] is hospital based but she can go and see patients down in you know, refer patients down in the holistic centre or the Macmillan information centre but some of the other things that she can provide as well, is when patients are having a procedure done and they're scared to have that procedure done and they don't want to come in, but she'll say she'll stay with them through that procedure and she has done so in the, when the patients had bronchoscopies etc, so she'll liaise with other departments if the patient's just a bit nervous about going in a scanner or having a biopsy, she'll go down with them." (P9: CNS)

> "The person we've got now at present, she's excellent. She's able to sort of ensure that a lot of things seem to get missed because we just don't have the time to make sure that people are sort of being reviewed on a regular basis and that we're able to catch up with people at a timely time in a timely manner and she is able to ensure that that is happening. She does have the IT skills as well which helps us to put different systems in place to ensure that we can coordinate better and has made us a lot more efficient. I feel a lot more sort of in control at work since she's been working with us in that I know that all the patients are being monitored, we know that they're

going to get reviewed at the right time and she seems to have put all of this into place herself … she's made a lot of difference even in a short period of time which allows us to then do some of the specialist treatments that we need to do and the specialist assessments that we feel that we haven't been able to do and also allows us to give time to look at survivorship because physios on our team have quite a big role in survivorship and ensuring that patients optimise their function and quality of life and I think we do have a big role to play. We always feel that we don't have time to spend on those patients but I do feel that with this part of a Care Co-ordinator we will be able to do that and potentially that has a huge effect on – in the longer term and you know if you improve people's health and wellbeing we're potentially going to reduce admissions to hospital, reduce admissions to, you know, attendance at GPs, so I could see it could have a huge long term effect, you know, on the whole service really. As well as you know patients are getting a better service and it's optimising their quality of life which is important." (P15: Neuro-oncology physiotherapist)

9.2: Community Sister

"Definitely quality of patient care and you know having some extra support for them but you know hopefully to prove the benefits of the post you know there will be things like you know people won't miss their appointments cos they'll understand what where they're going and what they doing and what's happening or they may not need extra appointments in the hospital because they've got a better understanding of the treatments and those kind of things cos I know it's difficult with post you've got to have more to support them so you know I can see that there maybe some saved appointments in hospital and saved phone calls to consultant secretaries and those kind of things because the service is a bit more joined up and the patient has a bit more of an idea of what they're meant to be doing." (P14: Palliative specialist nurse)

Theme 10: Sustainability challenges

10.1: CCC role

10.1.1: An impact on professionals and patients

"Our current cancer care co-ordinator is doing an absolutely fantastic job and even in such a very short space of time we can see a huge difference and I'm sure that that will continue. I guess some of these co-ordinators have been there for much longer, and I think you know over time I'm sure we'll see a much bigger difference and I really hope that they do get their funding to stay really. Cos I think it makes a big difference to us professionally and I really do think it does help the patient." (P5: CNS)

10.1.2: Not to replace nurses role

"They are of benefit to cancer patients and to specialist nurses working in cancer care definitely. I also think we need more nurses as well. I don't think that cancer care co-ordinators should be employed at the expense of more specialist nurses. But I recognise that nationally, there's a national shortage of nurses and there's a shortage of specialist nurses. But I don't think that

> cancer care co-ordinators should replace the nurses – I think there's a role for everybody in the team – and they do enhance the team." (P7: CNS)

10.1.3: Being a non-clinical role

> "The girls aren't, haven't got clinical training and I think there still, it's still a patient centred role and I think the clinical training is quite important. At the moment they don't have permanent contracts and as I say mines on maternity leave and our unit manager is trying to get that covered while she's on maternity leave and the trust are quite reluctant to cover that role because there's no, there's no proof that their role is working and I think that's a big challenge that we've got in the next coming months and the trust have looked at those IM's and there're not adequate enough." (P2: CNS)

10.1.4: Protecting the role professionally and legally by having a structured job description

> "What I would say is that the cancer care coordinators is that their core skills must be really clear you know, if the cancer care coordinator was to be in post permanently, I think your core skills have to be very clear because you know, they may say 'Uh well I don't think that's my job or that may might not be my job and I think the specialist team need to work with you know, the their own employer to set down a very structured job description for them so they're not taking off here there and everywhere as a pair of hands. … they're still not a registered nurse I think we've just got to be mindful that the you know, they don't have any formal legal registration to maintain, so it's a responsibility for the trust to make sure that they work within the guidance because I think I suppose I suppose I'm thinking of our cancer care coordinator, if the people please her if you like, she says 'yes I'll do that, oh yes to that' and she makes, you know, be coerced into by some senior grades, if you like, say 'oh, you do that yeah, yeah do that, I'll just check on it later and I think they have to re remain true to the job description and their capacity really." (P9: CNS)

10.1.5: Funding challenges and demonstrating the long-term impact of the role

> "I know the main challenge will be funding, and the Trust providing the funding support to continue. Obviously that – the only way they will do that is if they can see there's a benefit financially and I know that Macmillan have done a lot of work on looking at how using the matrix … it's obviously shows that it's allowed the health professionals that have – the skilled health professionals to free their time to spend more time with the patients using those skills, which obviously is going to be of benefit to the patient. What it won't show is what I was explaining about that long term benefit of reducing hospital admissions, reducing GP access and appointments. I don't think we will be able to show that from the matrix but I do think that is something that potentially that a Care Co-ordinator will do as part of the team, because I think as a team we do that, we prevent hospital admissions and we do improve quality of life and health and wellbeing so it just – it's not going to show that longer term effect unfortunately. But in terms of releasing the therapists and skilled health professionals to do their more skilled work, it certainly will be doing that." (P15: Neuro-oncology physiotherapist)

10.2: Community Sister role

10.2.1: More specialised role

> "I do know that the plans for those roles are to maybe be extended to a more specialist nurse type role and be more like nurse practitioner sort of could maybe you know, there may be other things that they could possibly diagnose and prescribe for but I don't I don't think that's happened yet, but I think that's where something that might go as well." (P9: CNS)

10.2.2: Belonging to a team

> "I think if we were all linked better together that would be good you know and you know I don't know what will happen in the future but you know if the cancer sister you know I would look at the cancer sister job as, as have to sit in some team and although it's, you know it's not a palliative job you know they've got to belong somewhere so I would see a kind of you know them belonging to us or belonging to the tumour specific groups or you know they have to belong somewhere and if there's going to be some natural, some natural referral pathways from them to us and us to them, you know those links are all really important." (P14: Palliative specialist nurse)