Evaluation of the South Yorkshire, Bassetlaw and North Derbyshire Survivorship Programme: Final Report

Macmillan Cancer Support

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A report submitted by ICF Consulting Services

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# Contents

Glossary of terms .......................................................................................................................................................................................... iv

Executive summary .............................................................................................................................................................................................................. v

1 **Introduction** ................................................................................................................................................................................................................................. 1

1.1 Aims and objectives of the SP and evaluation ................................................................................................................................. 1

1.2 Evaluation method ........................................................................................................................................................................................................... 2

1.3 Report structure ........................................................................................................................................................................................................ 2

2 **Contextualising and describing the SP** ............................................................................................................................................................. 4

2.1 More people are living with and beyond cancer than ever before ........................................................................................................... 4

2.2 Reforms are needed to align services with the needs of people affected by cancer ............................................................................. 5

2.3 The SP is seeking to implement the changes sought in policy .................................................................................................................... 7

2.4 The SP is also an attempt at ‘system change’ ......................................................................................................................................................... 12

3 **The SP in Sheffield** ......................................................................................................................................................................................................... 15

3.1 Improving the use of secondary care ................................................................................................................................................................. 15

3.2 Building capability in primary / community care ........................................................................................................................................ 20

3.3 Developing more holistic packages of support for PABC ........................................................................................................................................ 24

4 **Early PABC experiences of the revised pathways in Sheffield** ........................................................................................................................................ 27

4.1 Interviewees were unanimously positive about secondary care ........................................................................................................... 27

4.2 Those who attended the HW day found it helpful ......................................................................................................................................... 27

4.3 In general, interviewees felt well prepared for discharge ........................................................................................................................... 28

4.4 Primary care follow up is still at an early stage; relationships are important ............................................................................................ 30

4.5 Interviewees discussed the non-medical support they had utilised ........................................................................................................... 31

Reflections on the value of peer research ................................................................................................................................................................. 33

Peer researcher experience ........................................................................................................................................................................................................... 33

5 **Economic analysis of the revised pathways in Sheffield** .......................................................................................................................................... 34

5.1 Method ......................................................................................................................................................................................................................... 34

5.2 Calculations ........................................................................................................................................................................................................ 41

5.3 Results of the analysis ................................................................................................................................................................................................ 42

5.4 Recommendations for further research .......................................................................................................................................................... 46

6 **Summary of lessons from other areas** ............................................................................................................................................................... 47

6.1 Doncaster’s co-production approach has focused on building access to, and capacity in, community services ......................................... 47

6.2 Bassetlaw has worked with a VCS based survivorship team .......................................................................................................................... 49

6.3 To date, Barnsley has focused on care navigation ........................................................................................................................................ 49

6.4 Rotherham has trialled a 1-2-1 model in urology ..................................................................................................................................................... 50

7 **Lessons from across the programme** ............................................................................................................................................................... 51

7.1 There is a need for a clearer ‘programme theme’ ............................................................................................................................................... 51

7.2 Programmes of system change take far longer than ‘traditional’ programmes; they also require different skills and perspectives ........................................................................................................................................................................................................ 52

7.3 Macmillan has provided clear strategic added value through the SP .................................................................................................. 54

8 **Conclusions and recommendations** ................................................................................................................................................................. 55

Annex 1 Stakeholders interviewed ....................................................................................................................................................................................... 60

Annex 2 Stakeholder interview topic guides ......................................................................................................................................................... 62

Annex 3 Peer evaluation research tools ................................................................................................................................................................. 77

Annex 4 Cost of health and wellbeing day ............................................................................................................................................................... 85

Annex 5 Sources of data used in economic analysis ........................................................................................................................................ 86
Glossary of terms

CALM – Cancer Attitude and Life Management
CCG – Clinical Commissioning Group
CCR - Cancer Care Review
CEA – Carcinoembryonic Antigen
CIC – Community Interest Company
CN – Care Navigator
HCP – Healthcare Professional
HNA – Holistic Needs Assessment
HW – Health and Wellbeing
IAPT – Improving access to Psychological Therapies
LCS – Locally Commissioned Scheme
MYCAW – Measure Yourself Concerns and Wellbeing
NCSI – National Cancer Survivorship Initiative
PABC – People Affected By Cancer
PLI – Protected Learning Initiative
PROM – Patient Reported Outcome Measure
QIPP – Quality, Innovation, Productivity, and Prevention
QOF – Quality Outcomes Framework
RfD – Routes from Diagnosis
RtS – Redesigning the System
SAV – Strategic Added Value
SOHAS – Sheffield Occupational Health Service
SP - South Yorkshire, Bassetlaw and North Derbyshire Survivorship Programme
SPARC – Sheffield Profile for Assessment and referral for Care
STH – Sheffield Teaching Hospital
TS – Treatment Summary
VCS – Voluntary and Care Sector
Executive summary

ICF International (ICF) was commissioned by Macmillan Cancer Support to provide an independent evaluation of the South Yorkshire, Bassetlaw and North Derbyshire Survivorship Programme (the ‘SP’).

Fundamentally, the SP seeks to improve the experience and outcomes of people living with and beyond colorectal cancer. It was originally developed by a partnership between the former North Trent Cancer Network (NTCN) and Macmillan Cancer Support. Following the dissolution of the NTCN, the SP was then supported by a partnership of Clinical Commissioning Groups (CCGs) in South Yorkshire and Bassetlaw (‘COGCOM’).

The programme has been implemented through different activities delivered in different localities. In summary:

- Sheffield has focussed on system-wide change in implementing risk stratified pathways and a ‘recovery package’ of interventions to support self-management.
- Doncaster has adopted a co-production approach to eight workstreams aligned to outcomes defined by people affected by cancer.
- Barnsley has implemented a community based care navigator project.
- Rotherham has trialled a community based 1-2-1 support model in urology. This is going to be tested with colorectal cancer going forward.

These activities were established at different times and are at different stages of development. One of the defining characteristics of the SP has therefore been its variety. The SP is not a ‘single model implemented in different areas’; it is a set of thematically related activities that have been devised and delivered to meet specific local needs.

The programme has also evolved over time. The SP was structured in two phases with Phase 1 starting in 2011, and Phase 2 starting in the autumn of 2013. A Baseline Evaluation report, focussing on Phase 1 of the SP was produced in October 2013. This document is the Final Report from the evaluation, focussing on Phase 2 of the programme.

Aims and focus of the evaluation

Macmillan has made a strategic decision to stimulate and support ‘system change’: to make revisions to the way different services are set up and interact, rather than make improvements to single services. The SP is one of several efforts across the UK to achieve this. This is a new direction for Macmillan and this evaluation was therefore commissioned with a focus on learning – for Macmillan and others – about the process and results of affecting system change.

As noted above, services and activities under the SP have been implemented in different geographic areas, with different emphases and in different ways. The most developed plans for system-change have been implemented in Sheffield: risk stratified pathways which transfer follow-up care to primary care at two (colon cancer) or three years (rectal cancer) are being trialled here. Our evaluation therefore focusses more heavily on work undertaken in Sheffield.

Evaluation methods

The evaluation of the SP made use of a mixed methods design, drawing on qualitative and quantitative information. Research was undertaken in two stages. The first was undertaken in 2013 and culminated in a Baseline Report. The second stage, which produced the evidence base for this report, was undertaken in late 2014 / early 2015 and included:

- Forty stakeholder interviews – these were semi-structured and conducted either face-to-face or by telephone. Those interviewed included strategic stakeholders such as the programme team, pathway developers, and commissioners; and other stakeholders such as project leads and staff in secondary and primary care, social care and VCS support agencies.
- Peer research – We sought to include the perspectives of people affected by cancer in a meaningful and innovative way by involving them as peer researchers. Four people were recruited as ‘peer researchers’ through the Weston Park Cancer Information and Support Centre. They
were trained by an ICF trainer in two workshops. The peer researchers then interviewed 18 patients who had been discharged to primary care follow-up on the revised pathways. After interviews were completed, a final workshop was held to discuss findings and receive feedback from the researchers. Interviews were transcribed and analysed by ICF.

- Economic analysis – a cost comparison analysis was used to compare costs of the old and revised pathways implemented in Sheffield.

Findings and recommendations

The SP is ongoing. Many projects and activities are at an early stage of development, others are bedding down to become part of mainstream provision. The implication for the evaluation is a necessary limitation on what can be said about impact. Interpretation of findings should therefore be made with this in mind.

The main findings in the report are presented below; recommendations are summarised in blue boxes.

**The rationale for the SP continues to be strong: it should continue**

The programme has been implemented in a challenging context, which will continue to be relevant for the foreseeable future. The demands of an ageing population and a financially stretched public sector are now well rehearsed. Coupled with medical advances, this means there are an increased number of people surviving cancer. Latest figures from Cancer Research UK reveal that 50% of adults diagnosed with cancer in 2010-2011 in England and Wales are predicted to survive 10 or more years. This figure rises to 57% for those diagnosed with bowel cancer. In Sheffield alone there were 14,600 people living with and beyond cancer in 2010, and this is set to rise by 2030 to 28,500 people.

National policy presents a clear need for change in how those living with and beyond cancer are supported. The National Cancer Survivorship Initiative (NCSI) has been integral to these efforts by providing insights into what this change needs to look like. Fundamentally, care must change from a ‘one size fits all’ approach and patients need to be supported holistically beyond diagnosis and treatment.

The SP sets out to meet this need. It has taken significant steps towards changing patterns of care and increasing the role of more holistic provision. Macmillan’s role in this has been vital. They have led the ‘survivorship agenda’; advocated for the patient voice; made significant contributions towards bringing different parts of the system together; and been instrumental in promoting the required changes.

**There is therefore a role for Macmillan to continue to promote survivorship in the area through their influence on different parts of the system, and support to localities in implementing plans which make use of learning from across the programme.**

**The SP ‘evolved’ and was not strategically designed: the next phase should be more ‘deliberate’**

The programme has been implemented against a challenging backdrop. Structural changes in the NHS and the disbanding of the NTCN presented difficulties for continuity in terms of leadership and governance. Our findings have shown that the SP evolved from a set of discrete projects across the localities. These projects are connected by a broad focus on survivorship, and have been implemented at different stages of the programme. Although efforts have been made to share learning, there is little sense of a single, coherent ‘programme’.

**There is a need to revisit – and better align – project aims across the localities, to make for a more cohesive programme. The next phase should have a clearer thematic focus; generating and sharing learning across local areas should be seen as a primary function of the programme.**

**In Sheffield, efforts have been made to implement all four components of the ‘recovery package’**

The ‘recovery package’, developed by the NCSI is a set of four integrated interventions which support self-management. These include: 1) a holistic approach to assessment and care planning (a ‘holistic needs assessment’); 2) a ‘treatment summary’ which is completed at the end of each phase of
treatment and sent to both the patient and the GP; 3) a ‘cancer care review’ which is completed by the GP or practice nurse in order to discuss the patient’s needs; and 4) a patient education and support event (e.g., a Health and Wellbeing Clinic), to prepare the person for the transition to supported self-management.

Work in Sheffield sought to implement all four of these interventions. They have been put in place to varying degrees, with the embedding of the holistic needs assessment and the treatment summary being reported as important outcomes.

- The holistic needs assessment is seen as a useful tool for healthcare professionals to have more holistic conversations with patients. Healthcare professionals thought that: it aided patient self-management; as a result of its use patients are better prepared for discharge from secondary care; and, that there might be improved patient experience as a result of nurse inputs to the process of completing the assessment and care planning.

- Findings in relation to the treatment summary indicate that significant effort has gone into ensuring it is embedded and that it makes use of existing IT systems. The successful embedding of it has important implications for developments going forward – stakeholders indicated that there is now a template to work from when working in other tumour groups.

- Patient education delivered through a health and wellbeing day was also evaluated positively by participants, and there are plans to continue to run these in the future.

- The revised pathways for follow-up care are still at an early stage, with numbers being discharged onto these pathways currently being lower than expected. This has affected the testing of impact of the cancer care review in particular (with very few patients having received one at the time that fieldwork took place), yet early indications suggest there is further scope for ensuring it is embedded.

- Patient perspectives on the recovery package were gained from the peer research. This showed that, whilst the holistic needs assessment was not necessarily recognised as a discrete intervention, most interviewees considered that their holistic needs had been met in secondary care. Many also recognised the treatment summary as being useful for both themselves and the transfer of their care to GPs. A small number of interviewees had attended the health and wellbeing day, and had found this helpful in terms of access to dietary and physical activity information which helped them with self-management. We were unable to evaluate the cancer care review from the patient perspective, since none of the interviewees had received or knew that they were due to receive one.

**Risk stratification seems appropriate but takes time**

In Sheffield three new pathways were developed to replace a single pathway for people with colorectal cancer. These pathways were based on level of risk, with patients being assigned to these either two (colon) or three (rectal) years after diagnosis. Level 1-2 (low-medium risk) patients are classed as appropriate for discharge to primary care at this stage, whilst Level 3 (high risk) patients are kept under consultant-led care.

Early findings from stakeholder interviews and peer research in Sheffield suggest that there is broad support for the use of risk stratified pathways. This is also supported by economic analysis which suggests that the revised pathways are broadly cost-neutral.

Implementation of the pathways has however been without challenges. Our findings showed that clinicians in secondary care need to have confidence in, and advocate for change in, revisions to pathways. Primary care stakeholders also need to be engaged from the start so that changed practice can be embedded. Evidence from the peer research shows that whilst the majority of interviewees were accepting of earlier discharge into primary care, this also raised considerable anxieties for some – most notably in terms of changing to new processes (such as differences in keeping patients informed), and gaps in (informal) emotional support from healthcare professionals.

There remains scope for improving handover to primary care. Proactive communication appears especially vital to patients’ experience of this transition; this should be focused upon.
One of the key lessons from the SP has been that relationships across the system take time to develop. Implementing system change is an ambitious task. Significant efforts were made in Sheffield to engage primary care, through development of a locally commissioned scheme; learning and development activities; and dedicated support to improve systems. This meant that implementation took longer than expected.

**Engagement is fundamental to system change. Long term commitment from programme developers is required for changes to become properly embedded so that they are ‘business as usual’. We recommend that this would require a commitment of somewhere in the region of five to ten years, rather than the usual three to five.**

**Building in more holistic care requires engagement across the system – including with service users**

Different localities have adopted different approaches to system-wide change. The framework of ‘push and pull’ is useful in describing changes made in Sheffield and Doncaster. In Sheffield, the programme started in secondary care, building out into primary care and then wider services – helping services to reduce unnecessary use of secondary care. This approach can then be categorised as ‘pushing out’. In Doncaster, the programme started in community / voluntary services and is building into primary and secondary care. This can be thought of as ‘pulling in’. Doncaster has made use of community development approaches and Sheffield has acted on systems of care. Both approaches are likely to be needed to enact the system-wide changes desired.

Furthermore, experience from Doncaster has shown the value of adopting a co-production approach. The work done to engage people affected by cancer in defining outcomes and activities has been a powerful tool for generating engagement across the system.

The SP has also provided lessons as to how emotional and psychological support is utilised by people affected by cancer. Formalised / programmatic support is not always required even when people are going through emotionally demanding times. Informal support networks, and informal emotional support from healthcare professionals are greatly valued, as is flexible community-based provision.

Workforce development has been an important factor in making change: both in terms of formal training and learning, and in terms of the cultural changes / gains in understanding from bringing different people together ‘from across the system’.

**There are clear lessons from the SP on the process of changing systems. Specifically, the work in Sheffield and Doncaster suggests that a sequenced and combined approach of ‘push and pull’ is needed – as is engagement with patients and professionals. These lessons should be used in the next phase of the programme and in Macmillan’s wider work. The iterative approach to providing holistic support should also continue into the next phase of the SP.**

**More research is needed...**

It is an all too common recommendation of evaluations, but the early stage of the SP’s implementation really does suggest that more research is needed. Findings from this evaluation have indicated that drawing any firm conclusions on impact of the SP would be premature. In particular, the programme is still at an early stage in terms of impacts for patients.

As the SP moves into the next phase, it will remain important to develop robust mechanisms for monitoring and evaluation, and then to use the data generated from this to track short, medium, and longer term outcomes. It has been too early for example to comment on outcomes of earlier discharge in relation to morbidity, mortality, and detection of recurrences.

Finally, our economic analysis was also limited to a cost comparison exercise due to the early stage of the project. It was also limited to modelling intended, rather than actual, changes. Further research is therefore needed to assess how costs change as the pathways become further embedded. Moreover, commissioners will want to know how the level and distribution of cost changes as pathways are revised.
1 Introduction

ICF International (ICF) was commissioned by Macmillan Cancer Support to undertake an evaluation of the South Yorkshire, Bassetlaw and North Derbyshire Survivorship Programme (the ‘SP’). The SP was originally developed by a partnership between the former North Trent Cancer Network (NTCN) and Macmillan Cancer Support. Following the dissolution of that Network, it was then supported by a partnership of Clinical Commissioning Groups (CCGs) in South Yorkshire and Bassetlaw South Yorkshire (‘CCGCOM’1).

The SP was structured in two phases with Phase 1 starting in 2011, and Phase 2 starting in the autumn of 2013. This is the Final Report from the evaluation, focussing on Phase 2 of the programme. A draft was produced in February 2015, this was discussed with the steering group, before being revised to form this final version.

1.1 Aims and objectives of the SP and evaluation

The overall aim for this evaluation, as given in the terms of reference, was to:

“Provide an independent and robust assessment of the impact of and learning from the Survivorship Programme and the new models of care it is delivering.”

The specific objectives were to:

- “provide regular findings and evidence that help us to test whether the new models of care achieve better outcomes for people with cancer and better resource utilisation;
- draw out lessons learned on what works (and what doesn’t work), for whom, why and in what circumstances – to shape the development of the programme and inform future phases;
- facilitate the sharing of this learning among different stakeholders and the practical implementation of the findings (including locally and nationally, for other tumour sites and for other long term conditions); and,
- review the extent to which the Routes from Diagnosis analysis has helped to shape the programme/new models of care, and how it informs ongoing implementation.”

1.1.1 Limitations and focus of the evaluation

Several factors limit and focus this evaluation. These include the:

Nature of the programme

Fundamentally, the SP seeks to improve the quality and quantity of support for people living with and beyond cancer. In pursuit of this, services and activities have been implemented in different geographic areas, with different emphases and in different ways. Over time, the SP has evolved (and is still evolving) as new activities are implemented. This is not a ‘single model, attempted in different areas’. Nor is it ‘the finished article’: many activities are at an early stage of development, others are bedding down to become part of mainstream provision. The implication for the evaluation is a necessary limitation on what can be said about impact.

Level of evaluation

The evaluation was commissioned and undertaken at the programme level. It therefore takes the broad frame of improving survivorship support and the range of activities noted above. Yet, in order to provide a means of concentrating the resources available for the evaluation and thereby generate sufficient findings, it was agreed that there would be a primary focus

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1 A commissioning collaboration between Barnsley, Bassetlaw, Doncaster, Rotherham and Sheffield Clinical Commissioning Groups.
on Sheffield. This decision, allied to the early state of implementation in these areas, means that the other areas covered by the SP are noted, but do not feature heavily in this report.

**Purpose of the evaluation**

Macmillan has made a strategic decision to stimulate and support system change; this programme is one of several efforts across the UK to achieve this. The evaluation was therefore commissioned with a focus on learning – for Macmillan and others – about the process and results of affecting system change. What follows is presented with this focus in mind.

### 1.2 Evaluation method

The evaluation of the SP has made used of a mixed methods design, and included the following:

- **Consultation with 40 stakeholders** in either face-to-face (n=4) or telephone (n=36) interviews. Interviews were semi-structured and supported by topic guides which were agreed with the programme team in advance (see Annex 2). Stakeholders included strategic stakeholders such as the programme team, pathway developers, and commissioners (n=8); and other key stakeholders such as project leads and staff in secondary and primary care, social care and VCS support agencies (n=32). Interviews were conducted between November 2014 and February 2015.

- **Economic analysis** of the Sheffield work. A *cost comparison analysis* was used to compare costs of the old and revised pathways implemented in Sheffield. The analysis began with a workshop (held 14th October 2014) in order to map out the pathways. The workshop was attended by 15 stakeholders who were involved in designing and implementing the revised pathways. A framework for the analysis was then developed which set out the approach to be taken in the analysis, and was used to guide data sourcing.

- **Peer research.** This was an important element of the evaluation of the Sheffield work with revised pathways. It has made significant contributions to the overall evaluation, by proving a richness of data which might otherwise not have been gathered. We sought to include the perspectives of PABC in a meaningful and innovative way, by involving the peer researchers throughout the process of the peer research.

  **Four PABC were recruited as ‘peer researchers’** through the Weston Park Cancer Information and Support Centre. These researchers were trained by an ICF trainer in two workshops. Training covered material on the revisions made to the colorectal pathways, as well as research design and interviewing skills. Training was designed to be participatory and included role play and worked examples of interview scenarios to demonstrate the challenges that are associated with interviewing, both generally, and in relation to working with a potentially vulnerable group.

  The peer researchers interviewed **18 patients** who had been discharged to primary care follow-up on the revised pathways. Interviews were conducted between November 2014 and February 2015. ICF recruited patients through the colorectal team at STH, and worked with the peer researchers to schedule interviews. Email and telephone support was provided to peer researchers by ICF throughout the peer research. After interviews were completed, a final workshop was held to discuss findings and receive feedback from the researchers. Interviews were fully transcribed and analysed by ICF.

### 1.3 Report structure

The remainder of this report is organised in the following sections:

- Section 2 will set the scene by contextualising and describing the SP;

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2 See the Baseline Report from the evaluation.
Section 3 will explore evaluation findings of the SP in Sheffield, using stakeholder interviews and data produced by the programme;  
Section 4 will describe the findings from the peer research by presenting PABC’s early experiences of the revised pathways in Sheffield;  
Section 5 will present the economic analysis of the revised pathways in Sheffield;  
Section 6 will explore evaluation findings of the SP in Barnsley, Doncaster, Bassetlaw and Rotherham; and  
Section 7 summarises lessons from across the programme, aiming to guide the development of the next phase of the SP; and  
Section 8 will draw together conclusions from the findings, and make recommendations for the SP.

The following Annexes are also included:

- Annex 1 – Stakeholders interviewed;  
- Annex 2 – Stakeholder interview topic guides;  
- Annex 3 – Research tools for the peer research; and  
2 Contextualising and describing the SP

Section summary:
National policy presents a clear need for change in how those living with and beyond cancer are supported. The National Cancer Survivorship Initiative (NCSI) has been integral in providing insights into what this change needs to look like.

The localities participating in the SP have implemented a variety of projects to support survivorship, and are at varying stages of progress:

- Sheffield has focused on system-wide change in implementing the recovery package.
- Barnsley has implemented a community based care navigator project.
- Doncaster has adopted a co-production approach to eight workstreams aligned to PABC identified outcomes.
- Rotherham has trialled a community based 1-2-1 support model in urology. This is going to be tested with colorectal cancer going forward.

This section is descriptive, rather than evaluative. It 'sets the scene' of the SP by first briefly describing the national policy context and the need for the programme, before describing the programme itself. The SP is described in terms of the projects being implemented in Sheffield, Barnsley, Doncaster, and Rotherham. The description of the SP is based on findings from programme documents and local evaluation reports, augmented by our interview findings with stakeholders.

2.1 More people are living with and beyond cancer than ever before

In the UK today, there are over 2.5 million people living both with and beyond a diagnosis of cancer. With a growing and ageing population, this figure is expected to grow to over four million by the year 2030, particularly with progressively more effective diagnosis and treatment.

Latest figures from Cancer Research UK reveal that 50% of adults diagnosed with cancer in 2010-2011 in England and Wales are predicted to survive 10 or more years. This figure rises to 57% for those diagnosed with bowel cancer. Looking at 2012 figures, the number of new cases increased from the year before, by 4,300 for men and 2,600 for women, with colorectal - and breast, lung, and prostate cancers – making up over half the newly diagnosed cases in England. Looking at the local context of the SP, in Sheffield alone there were 14,600 people living with and beyond cancer in 2010, and this is set to rise by 2030 to 28,500 people.

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7 http://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/SurvivorshipPartnership.aspx
Overall, the last 40 years have witnessed cancer survival rates double in the UK, leading to cancer becoming increasingly seen as Long Term Condition (LTC). This re-framing of cancer can, for example, be seen through recent work to align the National Cancer Survivorship Initiative (NCSI) framework with that of the House of Care model for LTCs. Better alignment with other LTCs is even more important, considering that people living for longer with and beyond cancer are more likely to live with co-morbidities – which can sometimes be the consequences of cancer treatment. Despite this, evidence suggests that the current structure of health care provision is failing to meet the needs of cancer patients, in particular providing sufficient support to the increasing number of survivors.

2.1.1 National policy reflects a need for change

The national policy context is reflective of the changing nature of cancer. Current cancer strategies are giving increasing prominence to the ‘survivorship agenda’ and reforms are beginning to support the actions needed to improve outcomes and meet survivorship needs. Improving outcomes: a strategy for cancer (2011), which builds on the earlier Cancer Reform Strategy in 2007, covers the cancer journey from prevention to survivorship and end of life, recognising the rising number of people living with and beyond cancer.

This all fits under a broader umbrella of health policy literature centred around integration, personalised care and ‘care closer to home’ focusing on a shift of services into the community. ‘No decision about me without me’ is identified as the suggested guiding principle for survivorship support by ‘Living with and beyond cancer’. This includes, where appropriate, supporting patients to manage their own health and wellbeing which can help address unmet needs as well as reduce service demand.

2.2 Reforms are needed to align services with the needs of people affected by cancer

Recognition of the increasing incidence of cancer and improved survival rates has prompted several, broad service responses to begin to address unmet needs.

The NCSI – which ended in 2013 – aimed to ensure that those living with and beyond cancer are provided with the care and support needed to help them lead as healthy and active a life as possible. The NCSI Vision document identified five key shifts necessary to transform...
cancer care from a ‘one size fits all’ approach and improve outcomes for cancer survivors\textsuperscript{18}; these were a shift towards:

- Focus on recovery and well-being after treatment;
- Personalised care planning, information provision and holistic assessment;
- Self-management support;
- Tailored support for effects of treatment or further disease; and
- Measuring the experience and outcomes for cancer survivors, understanding their concerns and needs.

Building on this vision, in 2013 the NCSI published \textit{Living with and beyond cancer: Taking action to improve outcomes} which collated key learning around survivorship. It described piloted and tested interventions which were ready to be spread across the country to help improve the outcomes of survivors. This set out a five-step framework for survivorship to achieve the shifts identified above to improve survivorship outcomes and experiences (shown in Figure 2.1).

**Figure 2.1  Survivorship five-step framework, NCSI**

![Survivorship five-step framework](image)

\textit{Source: Living with and beyond cancer: Taking action to improve outcomes}

In addition, the report specifically introduced the idea of a ‘Recovery Package’: an integrated package of interventions, described in the box below.

**The recovery package: a national model**

The recovery package was developed by the NCSI to support self-management through improved outcomes and coordination for people living with and beyond cancer. The package is a combination of four elements:

- Holistic Needs Assessments and Care Planning at key points of the care pathway;
- A Treatment Summary completed at the end of each acute treatment phase, and sent to the patient and GP;
- A Cancer Care Review completed by the GP or practice nurse to discuss the person’s needs; and
- A patient education and support event (e.g. a Health and Wellbeing Clinic), to prepare the person for the transition to supported self-management. This should include advice on healthy lifestyle and physical activity.

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A two-year partnership between Macmillan Cancer Support and NHS England has been announced\(^{20}\). The ‘Living With and Beyond Cancer’ Programme will work to translate and embed the key findings and recommendations from the NCSI report into the mainstream commissioning and service provision landscape. The programme will focus on four priority areas:

1. Ensuring all patients have access to the survivorship ‘recovery package’;
2. Developing and commissioning stratified pathways of care supporting patients to manage their own health and wellbeing where appropriate;
3. Understanding and managing the consequences of cancer and its treatment and Patient Reported Outcome Measures (PROMs); and,
4. Promoting physical activity.

The programme is currently working with Strategic Clinical Networks and CCGs to progress the aim of embedding these priorities into the commissioning model through a number of different programmes\(^{21}\).

### 2.3 The SP is seeking to implement the changes sought in policy

The SP was developed within the above national context. It “is working to ensure that people living with and beyond cancer are leading as healthy and active a life as possible.”\(^{22}\) Within this the SP aims to take a holistic perspective in providing support for PABC beyond diagnosis and active treatment. The programme design benefitted from a history of local support from Macmillan. For example, in Sheffield Macmillan (with Age UK Sheffield) has funded posts to support service improvement for people with a cancer diagnosis who are aged over 50 years. Learning from this work helped shape the design of the programme, particularly in relation to engaging with other non-clinical services and using this to communicate the ‘message’ of the programme’s aims.

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\(^{21}\) Ibid

\(^{22}\) [http://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/SurvivorshipPartnership.aspx](http://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/SurvivorshipPartnership.aspx)
The SP was also designed within a local context of cancer pathways redesign. Establishing a shared vision has been supported by related local work, for example pathway redesign had already taken place in Sheffield for breast cancer. This provided both ‘process’ learning, and also helped people to understand the SP in terms of a broad direction of travel for changing cancer journeys.

The SP was not originally conceived as a single ‘programme’. It did not proceed from a single programme plan / funding stream / set of governance arrangements, etc. Instead, the SP was formed as a collection of commonly-themed projects in different local areas were brought together. There are therefore common elements across the localities – e.g. supporting patients to self-manage (where appropriate) in the community, and to upskill secondary, primary, and voluntary sector workforces in cancer survivorship awareness. Yet there are also strong local differences and localities have developed their own specific aims, objectives, activities, and desired outcomes.

The result is a complex programme. The Baseline report from the evaluation (October 2013) characterised the SP as “as a complex system operating within a complex system” which:

- “Contains numerous components, many of which interact – in some cases with clear interdependencies – but some of which are independent of each other;”
- Includes activities that are ‘traditional’ in that Macmillan is providing funding for agreed results, alongside activities are more strategic and less tangible in nature (influencing, coordinating, etc); and,
- Has a set of defined results that are expected to occur across a range of levels – from individual professionals to system-wide changes. Again, these results contain interdependencies.

Moreover, the programme does not operate in a vacuum. The external environment – primarily, but not exclusively, defined by the local health and social care economy – is in itself a highly complex environment. Complexity at this level can be understood in terms of interactions between the vast range of organisations (each with their own histories, objectives and capabilities). These interactions are mediated by – and evolve in response to - national and local policy, alongside other broad factors such as the changing nature of the original problem.”

Despite the SP’s complexity it is possible to identify key features which are common across the programme. The Baseline Report from the evaluation identified four key features of the SP, which are represented across the four localities (Sheffield, Barnsley, Doncaster and Bassetlaw, and Rotherham) to varying degrees:

1. A focus on survivorship;
2. Use of the patient perspective;
3. Taking a ‘system-wide’ approach; and
4. Risk stratification and, where appropriate, the promotion of self-management.

We set out below a brief description of the work implemented as part of the SP in each of the localities.

**2.3.1 In Sheffield the recovery package is being implemented**

Work in Sheffield has focussed on implementing the recovery package in support of risk stratified pathways. Patients are risk stratified according to three levels of risk either two (colon) or three (rectal) years after diagnosis. Level 1-2 (low-medium risk) patients are deemed appropriate for discharge to primary care at this stage, whilst Level 3 (high risk) patients are kept under consultant-led care. Once in primary care, Level 1 patients are monitored for carcinoembryonic antigen (CEA) markers every six months, and Level 2 patients are monitored in the same way but also receive an additional Cancer Care Review (CCR). Primary care interventions are supported through a Locally Commissioned Scheme (LCS) which all GP practices in Sheffield are signed up to.
The recovery package implemented in Sheffield is closely aligned to the national model (see Section 2.2) and contains:

- **Holistic Needs Assessment (HNA) and care planning** – Whilst still under secondary care a HNA is completed with patients at least twice; once at diagnosis and again at the first nurse-led follow up appointment (either 3 or 9 months after diagnosis, depending on treatment type). Additional HNAs may be completed depending on individual patient needs. HNAs are self-completed by patients using the Macmillan Concerns checklist (at diagnosis) and the SPARC (Sheffield Profile for Assessment and Referral for Care) tool. Nurses create a care plan based on the needs identified in this.

- **Treatment Summary (TS)** – This is sent to patient and GP (via NHS mail) at the point of discharge into primary care. The TS is a 3-page summary which contains information on diagnosis; disease staging; treatment received; possible long term consequences; needs identified by the HNA; when the next blood test for CEA markers is due; and whether/when a CCR is due.

- **Cancer Care review (CCR)** – This is a review of the patient’s care plan for patients who have been stratified as Level 2. The CCR is conducted in primary care (supported by a standard template), six months after discharge from secondary care.

- **Health and Wellbeing (HW) day** – There has been one event held in 2014, with plans to hold one or two events a year thereafter. The event was held in a central location in Sheffield with lunch provided. Patients who were in secondary care follow-up were invited. The event included education and information on the importance of healthy lifestyle and physical activity. Going forward, this will now be piloted as a ‘long term conditions’ health and wellbeing event.

As well as the recovery package, there are also a number of additional projects which support the new pathways:

- **1-2-1 Support service pilot** – A ‘Macmillan Primary Care Nurse’ works alongside primary care colleagues to support them in changes implemented by the revised pathways. The nurse provides support in completing the CCRs for colorectal (and breast) patients in primary care. The nurse either supports practice nurses in completing the CCR or conducts it herself. The project supports people to self-manage through signposting to existing resources. This project is independent to Macmillan’s national 1-2-1 programme.

- **Workforce education and development** – This has included developing specific sessions and university modules, as well as preparation for all levels of primary care for the revised pathways in the form of events and specific training sessions for GPs and practice nurses, and ‘listening and responding’ sessions for practice receptionists. In 2014 a total of 53 primary care staff participated in these education and development sessions. It has also included training previously in appreciative enquiry, and now in motivational interviewing (MI) as the chosen approach to supporting patients in a more ‘empowered’ way. MI training is run as a two-day training course for HCPs from all sectors (primary/secondary/voluntary). So far four courses (out of a set of six) have been run, with a total of 69 people trained.

- **CALM project** – Patients are referred to the CALM course whilst still under secondary care follow-up. The course is a four-week programme of support designed to enhance recovery and self-management. Course content includes adjusting to life after treatment; coping with worry of recurrence; coping with being discharged from hospital follow-up; communicating with friends, family and professionals; stress and coping strategies; and making plans and looking forward. Three courses have been delivered during the SP so far and each has been tested at different stages of the pathway (before discharge; at a mid-way point during secondary care follow up; and immediately following treatment).

- **Working through cancer** – Macmillan is working with the Sheffield Occupational Health Advisory Service (SOHAS), which is a pre-existing job retention service affiliated with
Sheffield GPs and the CCG. The project works across primary and secondary care to support PABC at two levels:

- **Level 1** – All patients who are in work or have the potential to work are asked about their employment, and receive information and signposting.
- **Level 2** – People with specific concerns or worries are provided with resources to support self-management.

**Physical activity and cancer** – ‘Active Everyday’ is a partnership between Macmillan Cancer Support, Sheffield Hallam University, Move More (Sheffield local authority) and Sport England. Led by Sheffield Hallam University, the project has adapted a model developed by Macmillan that enables health and social care professionals to support people to become and stay active. As part of the project, physical activity instructors across the city have been trained to be exercise specialists in cancer rehabilitation. With their help people affected by cancer are encouraged to become active in a way that best suits their needs and that they will enjoy. This can range from everyday activities such as dog walking, joining an exercise class, or taking up a new sport.

The project plugs into existing opportunities for physical activity in the community, but also supplements this with tailored exercise packages (e.g. young people with disabilities/walking project). The project is being promoted to PABC by hospitals; physiotherapists; cancer awareness and survivorship groups; and GPs. Once PABC are referred to the project, an assessment of need and wishes is made. PABC will then be referred to one of three physical activity pathways:

- Help and guidance to support independent exercise;
- An exercise referral route where support from an exercise professional will assess which physical activity is safe to do; and
- Signposting to access community based activities.

**Macmillan Age UK Independent Living Coordinators** – This is a project run by Sheffield Age UK, targeting those with complex lives and multi-faceted problems. The targeted cohort includes people living with cancer, who are most at risk of health decline and/or unplanned hospital admissions. The service forms part of the solution to the challenges currently faced in health and social care, in particular in the way it seeks to help to prevent unnecessary admissions and facilitate early discharge once treatment has concluded. Coordinators work to find solutions to whatever issues are affecting someone’s ability to self-manage health conditions; to support them to live independently; and to reduce isolation.

**Complex case managers** – The 1-2-1 complex case manager project aims to improve: the patient experience of care, allowing patients to be discharged (and remain discharged) from hospital; and the coordination of care, and communication between organisations. The target group for the service is diverse, although patients are predominantly end-of-life/palliative and have cancer. The service provides intensive, time limited, support to patients, helping them to be discharged from hospital. Two band 7 nurses have a high degree of autonomy to work with a variety of agencies and organisations to ensure that patients can leave hospital rapidly, and be supported once they are home. The range of services which the complex case managers work with include the hospital palliative care team; transfer of care teams; primary; community; and voluntary sector services. A separate evaluation of this project is being carried out by ICF, and an interim evaluation report was produced in April 2015. This project is independent to Macmillan’s national 1-2-1 programme.

### 2.3.2 Doncaster has adopted a co-production approach

In Doncaster there has been a fundamental emphasis on implementing change against needs identified by people affected by cancer (PABC). Ninety-six PABC were involved in determining key outcomes. Eight ‘I statements’ were developed against these outcomes to
identify areas which required change to better support PABC. These areas of work align well to Macmillan's nine outcomes, as shown in Table 2.1.

### Table 2.1 Eight ‘I’ statements map onto Macmillan’s nine outcomes

<table>
<thead>
<tr>
<th>Domain</th>
<th>‘I’ Statement</th>
<th>Macmillan outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Money</td>
<td>I fully understand the impact of cancer on my financial security (whether as patient or carer) and I have a well informed plan to cope with any insecurity.</td>
<td>I understand so I make good decisions. I know what I can do to help myself and who else can help me. I can enjoy life.</td>
</tr>
<tr>
<td>Employment</td>
<td>I am supported to maintain my working life for as long as I need or wish throughout my cancer journey.</td>
<td>I understand so I make good decisions. I know what I can do to help myself and who else can help me. I can enjoy life.</td>
</tr>
<tr>
<td>Information</td>
<td>I understand my health and can make good decisions throughout my cancer journey.</td>
<td>I understand so I make good decisions. I know what I can do to help myself and who else can help me. Those around me are well supported. I want to die well.</td>
</tr>
<tr>
<td>Health &amp; Wellbeing</td>
<td>I understand my health and know what to do to keep myself healthy and to live my life to the full throughout my cancer journey.</td>
<td>I understand so I make good decisions. I know what I can do to help myself and who else can help me. I can enjoy life. I feel part of a community and I’m inspired to give something back.</td>
</tr>
<tr>
<td>Carers</td>
<td>As a carer, I understand the impact of cancer on key aspects of my life, including my relationship with the person I support, and I know how to help myself and who else can help me.</td>
<td>Those around me are well supported.</td>
</tr>
<tr>
<td>Support</td>
<td>I know how to help myself and who else can help me to stay as healthy and independent as possible throughout my cancer journey and I am in control of my care and support.</td>
<td>I get the treatment and care which are best for my cancer and my care. I know what I can do to help myself and who else can help me. I feel part of a community and I’m inspired to give something back. I want to die well.</td>
</tr>
<tr>
<td>Discharge</td>
<td>When being discharged after being in hospital as an inpatient, I know how to help myself and who else can help me.</td>
<td>I get the treatment and care which are best for my cancer and my care. I want to die well.</td>
</tr>
<tr>
<td>Role of professionals</td>
<td>I get the care and support that enables me to live my life to the full throughout my cancer journey.</td>
<td>I was diagnosed early. I get the treatment and care which are best for my cancer and my care. I am treated with dignity and respect. I want to die well.</td>
</tr>
</tbody>
</table>

The above ‘I’ statements have been translated into eight workstreams, which have implemented a range of services. For example:

- There is a single point of access – through a ‘Living Well hub’ – to a network of over 80 local services including welfare and benefits advice, information on social groups, and emotional support. Both HCPs and PABC can refer into the service. The hub is staffed by seven workers, three of whom have been funded by Macmillan, and four by the CCG. The service works with a Community Interest Company (CIC), ‘Meeting New Horizons’ which supports PABC with social needs: a collaborative approach to assessment and supported signposting is adopted by the CIC.
Work to support colorectal cancer survivorship in primary care is just beginning in Doncaster. Two GP facilitators are visiting practices to raise awareness of cancer survivorship, and explain elements of the recovery package such as the TS and the CCR. There are no plans thus far to commission primary care to implement revised pathways.

2.3.3 Work in Rotherham will be extended from urology, into all cancer MDTs, including colorectal cancer

Rotherham has been trialling a 1-2-1 model based in the community with people affected by urological cancers. This model will now be tested with other cancer MDTs. The objectives of the project have been to improve care coordination, support PABC with holistic assessments, and to reduce emergency admissions. The project has included three workstreams:

1. **Profiling the workforce** – three workshops were held to bring together professionals from across different sectors in order to identify patient survivorship needs. Discussions centred on the use of care planning, assessment; record keeping; and support for carers/families.

2. **Piloting a model of care** – The profiling work was used to develop a model of care with two roles funded by Macmillan: a community based liaison nurse, and a cancer support worker. The new service coordinates holistic care planning across the system, incorporating care planning throughout the pathway from the point of diagnosis. The service supports recovery and independence, and is able to signpost PABC to a range of support and information services both within health and social care, and within voluntary and community organisations.

3. **IT solutions** – Methods of reducing the need for unnecessary follow-up appointments in secondary care are being looked at. Remote monitoring and integrated record keeping between acute and community trusts is also an area of current work.

In addition to these three workstreams there are plans to implement an MI training course in support of HCP learning and development. A HW day for PABC is also being planned.

2.3.4 Barnsley work has focused on the care navigator project

Barnsley has trialed a telecare model of survivorship making use of care navigators (CNs) based in community services. The service provides motivational health and wellbeing support to people affected by colorectal (and also breast and prostate) cancer. The team of 11 care navigators are nurses who provide personalised support tailored to patient needs. Self-management is promoted further by access to tools which can be used to monitor their conditions at home. Patients are referred to CNs after a year of hospital based follow-up. Early in the process CNs link in with the specialist nurses providing follow-up care to patients. This ensures a 'feedback loop' between patients and care-givers, which ensures eventual safe handover to CNs.

Survivorship work is still at an early stage in Barnsley, with this being taken forward by a recently formed project strategic group, made up of PABC and representatives from health, social care and voluntary sectors. Planning at this stage is considering risk stratification and primary care follow-up. Existing local mechanisms may act as levers for commencing work in this area; for example shared care protocols, enhanced services agreements, and a ‘Barnsley Quality Framework’ (using a localised Quality Outcomes Framework (QOF) have been previously used as mechanisms for change in primary care.

2.4 The SP is also an attempt at ‘system change’

Macmillan has taken a strategic decision to affect system change. In 2011, the then Chief Executive, Ciarán Devane, launched this change of direction as ‘Redesigning the System’ (RtS):
“Macmillan will work with partners to change the cancer system to ensure all cancer services - in hospital and the community, providing medical, practical, emotional and financial support - are joined up and designed around individual needs. We will need to look at the whole pathway in an area, not just parts of the pathway.”

RtS, which the SP is part of, has been developed in different areas of the UK. Local programmes have specific areas of focus, but all are united in an attempt to work ‘system wide’ to achieve improvements in patient experience and outcomes. Macmillan is making deliberate efforts to learn from local experience, feeding lessons back into strategic decision making and local programming; evaluation has played a central role in this.

The system-wide perspective taken within RtS has fundamental implications for:

- **Programme development and delivery.** System change is a complex proposition. The very nature of systems – comprising multiple interactions between multiple actors (with multiple and differing purposes, histories, incentives and perspectives) – means that the process of change is very different from Macmillan’s more traditional service development; and

- **Evaluation.** The complexity described above presents a fundamental challenge to evaluation methodology, much of which has also been designed around the assessment of single interventions. In particular, the non-linear nature of systems means that evaluation must, as a minimum, adopt a similar logic and take a broad view of change.

These issues, which are rehearsed more fully in the Baseline Report, have led the evaluation to adopt a systems perspective. As such, rather than summarising the SP in a standard ‘logic model’, a ‘system map’ – shown at Figure 2.2 - has been used. This has several advantages, for example it:

- shows the multiple interventions within the SP as they act on different parts of the system (primary, secondary, community, and voluntary sectors) as well as the interface(s) between these parts. It also – through the green background – shows that some interventions are ‘system wide’, rather than acting on specific elements of the system;

- provides a common framework for understanding some of the very different activities within the SP, by showing their common intentions and place within the system;

- shows the desired outcomes – both at the level of the ‘system part’ (e.g. primary care) and the system overall;

- shows interdependencies within the system – e.g. that for the programme to achieve its aims, ‘x’ must happen in primary care in order for ‘y’ and ‘z’ to successfully take place in secondary care; and, therefore,

- illustrates the nature of the task facing the SP in trying to make change across this system.

It should be noted that the map presented below is a representation of ‘the programme’; as noted above, this means that some elements of the SP will be present / lacking in each of the different areas.

[accessed February 23rd]
Figure 2.2  The SP as a ‘system map’

**System-wide interventions:**
- Stakeholder / system engagement – including commissioners; promotion of ‘survivorship agenda’; Programme comms and engagement work; Workforce learning and development
- Treatment summaries

**Secondary care**
- Care becomes more stratified / tailored
- Better recognition of survivors’ holistic needs
- Improved workforce skills
- Reductions in unnecessary follow-up appointments

**Patients**
- Better experience of / more access to holistic care
- Improved knowledge of condition / Increased ability to self-manage
- Care provided closer to home
- Supported returns to work
- Increased input to service design

**Primary care**
- Improved communication with secondary care
- Better systems for managing patients with cancer
- Increased ability to monitor / follow-up patients (increased role in doing so)
- Improved workforce skills

**Wider support services**
- Voluntary and community sector and other support services (e.g. physical activity) becomes ‘part of the pathway’
- Employers more engaged / supportive
- Improved workforce skills – understanding of holistic needs

**Community services / social care**
- Improved communication with primary care and secondary care
- Better links with voluntary sector support
- Increased ability to manage patients; more care delivered closer to home

**Key:**
- Patient flows promoted by SP
- System links promoted by SP
- Services / outcomes
- Patient outcomes
- Programme interventions

**System-wide impacts:**
- More integrated services with more care delivered in community settings
- Better skilled workforce
- Better use of resources
- Cultural change / understanding of holistic needs
- Lessons for other LTCs / cancers

**Routes from Diagnosis:** support for pathway redesign; Holistic Needs Assessment, care planning and ‘moving on’ interviews

**Health and Wellbeing events; referral hubs**

**VCS engagement; employment support; physical activity services**

**Staff training and engagement; tools and support for primary care; 1:2:1 support; primary care change agents**
3 The SP in Sheffield

Section summary:

The SP in Sheffield sought to make system-wide change in how survivorship is supported in follow-up pathways. Risk stratification of these pathways was central to this; implementing this in practice has been challenging.

The components of the recovery package have been put in place to varying degrees, with the embedding of the HNA and the TS being reported as important outcomes. The HW day was also evaluated positively by participants, and there are plans to continue to run these in the future. The revised pathways are still at an early stage, with numbers being discharged into primary care being lower than expected. This has affected the testing of the CCR in particular, with early indications suggesting there is still further scope for ensuring it is embedded.

Impact on cultural change has been strong in secondary care, but this weakens in primary care, partly as a result of the early stage of changes being implemented here.

The SP in Sheffield has adopted a system-wide approach. This comprised a number of projects, implementation at different times and points in the system, designed to make the whole system more efficient and effective in delivering holistic patient care. This involves making more appropriate use of both primary and secondary care – both from a patient perspective and from a health service perspective – and putting more holistic packages of support around the patient. A number of approaches have been utilised to support this change, making better use of existing support and establishing new areas of work.

This section is structured according to the major changes implemented in this system, presenting findings in relation to the rationale/design; implementation; and outcomes of the SP. Outcomes are reported where possible at the levels of patients; HCPs; organisations; and the local system. Sources of information used in this section are the stakeholder interviews and local evaluation reports.

3.1 Improving the use of secondary care

The rationale for improving the use of secondary care is well rehearsed. The need for this was described by interviewees in terms of increasing demands on secondary care in the light of a growing population and improved survival rates – and ongoing resource constraints. Patient experience was also integral to this rationale, with many interviewees commenting on how care closer to home (and therefore in primary care) is often more convenient and better for patients ‘moving on’ from cancer diagnoses and treatments.

3.1.1 The starting point was the design of risk stratified pathways

Risk stratification of pathways was a fundamental design feature of the work in Sheffield. Interviewees cited a range of more specific arguments in favour of using a risk stratified model:

- **Benefits to patients** – the model allows for meeting patient needs more appropriately. In a ‘one size fits all’ approach, some patients receive more care than they need, whilst others receive less.

- **Better planning** – There is the potential for using resources more efficiently based on a better understanding of needs at the outset.

- **Lever for change** – one stakeholder commented that within the context of a financially constrained NHS, the model allows for a mechanism for investment across the NHS: “It’s the only lever the programme has to release resources to invest elsewhere.”
As described in Section 2, three pathways defined by level of risk were implemented. The model differed from the national model of risk stratified pathways, in that patients were not stratified at diagnosis, but at two/three year follow-up – i.e. at the point of discharge into primary care.

Placing risk stratification at two/three year follow-up was considered a “safety net” by secondary care clinicians: most reoccurrences take place within the first two or three years after diagnosis, so would already have been picked up in secondary care before discharge. The two-three year time-lag also gave sufficient time in which to prepare primary care for their eventual duties in relation to Level 1-2 patients, and also to educate patients on the signs and symptoms of reoccurrence.

The ‘Routes from Diagnosis’ analysis was not used as intended, but did form an important design input

The rationale for risk stratification rests in the need for moving from a ‘one size fits all’ approach to a more tailored model of support for individuals. Stratifying patients by level of risk would then allow for assessment of patients according to their suitability and preference for survivorship services following the end of treatment. It would also allow for more intensive resources to be directed to higher risk groups.

Within the SP, the ‘Routes from Diagnosis’ (RfD) project provided evidence for risk stratification. RfD was first established by Macmillan (in partnership with National Cancer Intelligence Network and delivered by Monitor Deloitte) at national level. It draws upon mapped patient survivorship journeys following a cancer diagnosis for colorectal cancer, multiple myeloma, and Hodgkin’s Disease. Linked data from Cancer Registry and Hospital Episode Statistics inpatient records were used to chart different pathways and outcomes.

For colorectal cancer, data from a cohort of 6,509 patients diagnosed in 2001 (second quarter) were analysed. Collaboration with a clinical expert panel defined the relevant outcomes, which included duration of survival after diagnosis, co-morbidities, and burden of disease. Eighteen outcomes were defined for colorectal cancer, which were used to represent ‘risk strata’.

The RfD outcomes framework was subsequently tested locally using data from patients diagnosed with colorectal cancer between 2006-2008 in the NTCN area. This work found that underlying patterns remained the same for these local, more recent, data.

In order for this local analysis to be used as a design input (to translate the analysis into patient pathways) the outcomes were simplified to replace the original 18 outcomes with eight. These eight outcomes were then further aggregated – again for practical purposes - into three cohorts. The final local stratification therefore included: a ‘low-maintenance’ strata for a cohort where patients had no complications following their cancer; a ‘medium maintenance’ cohort, where patients faced non-cancer related complications to their recovery, and a third cohort, where patients had terminal cancer, and faced cancer-specific morbidities.

Stakeholders shared their views on the use of the RfD project. On the whole it was thought that the RfD work had been useful in the early design of the SP. This supports findings from the baseline report for the evaluation, which showed that analysis developed by RfD was seen as locally valid, and supported a focus on system-wide redesign (rather than a sole focus on self-management and survivorship).

24 The RfD project itself was part of national survivorship work conducted in 2009/10 by the Department of Health and Macmillan. The research aimed to map patient survivorship journeys following a cancer diagnosis for colorectal cancer, multiple myeloma, and Hodgkin’s Disease. Eighteen outcome groups were identified by the research.

In the final evaluation, one stakeholder commented that RfD had been influential in determining the “track” that the programme had taken, but that risk stratification could not have been implemented as presented in the analysis – for example with risk stratification taking place at diagnosis: “What was very clear in the work around Routes from Diagnosis...was a lack of confidence...secondary care clinicians were expressing concern, so was primary care, patients were expressing concern – if we were to suddenly implement a risk stratified pathway”. This reflects a lack of confidence in the methodology used in the RfD work, rather than in the principle of risk stratification per se.

The SP has not retained a focus on this early work however (for example by delaying risk stratification to later in the pathway, and not using it to plan services), and a number of stakeholders noted the limits of the RfD work. Most notably, application of the 18 outcome groups presented difficulty for the local team, and as such these were simplified first to eight, and then to the three current pathways - as described above). The data which this work was based on were also limited – with primary care data not being able to be included, as this was not accessible due to system challenges.

The key challenge to implementing risk stratification has been defining risk level

The experience in Sheffield has highlighted the substantial practical challenges inherent in moving from the retrospective analysis presented in RfD (which shows what may be possible in principle) to prospective clinical decision making.

Patients began being allocated to the new pathways in April 2014. By mid-November 2014, there were 281 patients with colorectal cancer who could have been allocated to the new pathways. Of these, 69 patients were discharged onto Levels 1-2 (25%), and 126 (45%) onto Level 3. A further 75 patients (27%) had not yet been allocated onto the new pathways, despite being eligible for this. The remaining 11 patients (4%) were patients who were not stratified because they were non-Sheffield residents, had moved away, or had not wanted hospital care. Of those that were risk stratified onto the new pathways (n = 195), 35% were discharged to primary care (Levels 1-2), and 65% remained in secondary care (Level 3).

In practice, allocating patients to the different pathways has been more straightforward for Level 3 patients (based on presence of metastases), but somewhat challenging to differentiate between Level 1 and 2 patients; as one interviewee noted: “We thought in the beginning it would be clear, but in practice it’s not.” This lack of clarity became a little clearer as the programme progressed. For Level 2 patients ‘risk’ is defined in terms of holistic needs rather than risk of reoccurrence: “It has to be something the GP can do something about.”

Part of the challenge with allocation may be explained by stratification being based on HCPs’ judgement of holistic needs. This means that allocation is more subjective and based on the: “Feel for the patient’s additional needs.”

In practice most patients (as of mid-November 2014) have been discharged as Level 1 patients (n = 66), with only a small number (n = 3) being discharged as Level 2. Several stakeholders reflected that the figures in each of the cohorts are very different to those expected at the outset; patients discharged onto the stratified pathways (at Levels 1-2) representing only a third of the number expected. This may be explained by other components of the revised pathways – such as the HNA which will have taken place at various points before discharge, as one interviewee commented: “By the point of discharge we should have addressed their concerns and issues, and if we haven’t should we be discharging them?”

Outcomes were discussed for earlier discharge

Earlier discharge from secondary care – at two/three years post-diagnosis rather than five years – is integral to the risk stratified pathways. Those at Levels 1 and 2 are categorised as low or medium risk and are therefore discharged into primary care after two/three years of follow up in the hospital. Some stakeholders were able to reflect on the extent to which earlier discharge is leading to outcomes. These included the following:
Helping patients to move on – Many stakeholders described how earlier discharge was better for patients, in terms of avoiding unnecessary appointments, encouraging independence from the hospital, and helping them to move on from the label of a cancer diagnosis: “We are giving them the information and knowledge to self-manage and not rely on us as much as the older patients [those on the old pathways] did…we are giving them the opportunity to live with and beyond the diagnosis - and the knowledge to move forward and get on with their lives.”

The reduced length of follow-up in secondary care may not necessarily free up capacity – Some stakeholders commented that earlier discharge is starting to free up capacity for the colorectal team at Sheffield Teaching Hospital (STH). However others suggested that this is not necessarily the case since the revisions require more intensive inputs: “We have cut down dramatically on the number of out-patients we are seeing…[but] in some ways the way we do things now gives us more work…so there are the care plans and more patient letters go out than before…we are also having a few problems with the CCG, a lot of emails going back and forth giving us a lot of extra work…this is to do with the patients we have discharged and discrepancies about numbers that have been discharged and where patients have gone…so there has been a lot of paper trawling.”

These two outcomes also reflect to some extent the tensions within culture change in secondary care. Where HCPs are displaying a better understanding of holistic needs – by helping patients to ‘move on’ and supporting self-management – they are also required (at least in the short term) to provide more intensive inputs.

3.1.2 The Holistic Needs Assessment embodies a new ‘holistic’ approach to care

The HNA forms one of the four core components of the recovery package (see Section 2). Its main function is to identify patient needs – including those that are non-medical – and to facilitate supported self-management by building in (or signposting to) support against these needs. This type of holistic care involves a collaborative approach where HCP and patient work together – in care planning – to plan how needs can be met. Within this project a collaborative approach to the HNA and subsequent care planning has been supported by training for HCPs in MI (see Section 3.2.4), thereby embedding a changed culture where holistic needs are better understood.

The HNA in Sheffield has been primarily conducted by the colorectal team based in secondary care. As well as using the HNA as a tool for holistic care, it has also used to base risk stratification for Levels 1-2 patients on.

Implementing the HNA has been challenging in terms of adjustment to change in process, and also in shifting to a more holistic culture. The first follow-up appointment with a nurse for example now takes an hour in comparison to the 20 minutes allocated to this on the old pathway. It was however felt by strategic stakeholders that these challenges have been largely overcome and that shifts in culture have been made within secondary care, leading to an embedding of the HNA, and a broader understanding of holistic needs. The Macmillan funded project lead was described as a key facilitator for supporting this change to take place. One stakeholder reflected that this role helped make “change happen”.

Interviewees commented that the holistic approach was starting to become embedded, and a number of early outcomes were reported for the HNA (and the holistic approach more generally). These illustrate that impact on culture change – towards a culture where holistic needs are better understood – is now being seen. Reported outcomes included:

A tool for HCPs – the HNA allows for a more holistic conversation, and for HCPs to identify patient needs and use this in care planning with patients. The HNA is mailed to patients before they attend follow-up appointments with the colorectal nurse at key trigger points (i.e. at first nurse follow-up appointment and discharge). Patients are asked to post this back to the colorectal team in advance of their appointment. The nurse then creates a care plan based on identified needs, and discusses this with the patient when they are next seen.
Patients are better able to self-manage – Due to the embedding of the HNA, care planning, and a more holistic approach throughout the pathways, stakeholders reported that by the time patients are discharged many of the non-clinical issues have been resolved. The patients are better able to self-manage as a result and this could have a knock-on effect on how primary care is subsequently utilised by them – i.e. by engaging with primary care HCPs in a more empowered way. Upon discharge they are given a booklet which details what support they should be getting, and they are advised to take this to GP consultations to talk about any support needs.

Patients are more prepared for discharge – Using the HNA and care planning as part of a holistic model of care has allowed for different consultations to take place, thereby illustrating the effects of culture change in secondary care. HCPs reported how they have observed that patients on the new pathways have not had the same anxiety about discharge that patients on the old (and longer) pathways had: “The consultation style is different. It used to be around a medical model. Because this is about a care plan in the first instance and the final instance it’s structured around the patient - letting them talk rather than you sitting asking the questions, writing it down, all the letters were the same. This is a lot more interactive.”

Improved patient experience – There is early / limited evidence to suggest that patients value the new process. For example, the CALM course report produced by the Weston Park Cancer Support Centre describes how those attending the course had valued the HNA and the time spent in the nurse-led clinic.

3.1.3 The Health and Wellbeing day was positively evaluated

The HW day or ‘roadshow’ is integral to the recovery package (see Section 2) in its preparation of PABC for self-management. The purpose of the event (held in May 2014) was to provide PABC with information on support services: 25 stallholders were present, comprising of voluntary and charitable organisations (national and local); NHS providers (e.g. IAPT, physiotherapy); local authority providers (e.g. health trainers); and a small number of private providers (e.g. those supplying specialist appliances/clothing for stoma patients).26

Interest in the event was slow to start with, but registrations were increased following an extension of the patients targeted to include all those diagnosed with colorectal cancer in the last two years. The event was also advertised through the local colorectal cancer service; a local cancer support group; social media (national charities posting on twitter and facebook); local radio; and GP practices. A total of 29 patients and 14 carers attended the event.27

Interviewees reported that the event had been positively evaluated. The internal evaluation report confirms this. The majority of PABC who completed an evaluation form (86% response rate), reported that they felt better informed about local services (90%), and that they had found new ways of “making themselves feel better” (91%). Nearly all (98%) PABC who responded reported that they would recommend the event to others. Over half (56%) the PABC also attended “feel good” therapy sessions, with half of these attending a “gentle exercise” session. Stallholders also evaluated the event positively (average score of 8 out of ten), stating that it had been valuable networking for them.

The internal evaluation also found that the cost per head of PABC attending was £54 – compared to £71 for the cost of a routine colorectal cancer outpatient follow-up appointment (see Annex 4). The report therefore concludes that replacing an appointment with the HW day is worth considering. Interview findings suggest that based on the positive feedback, the HW day is set to continue at least annually. Having one event a year may require further

27 Ibid.
reflection however, since this means patients could potentially have a long wait before they have the opportunity to attend it.

3.2 Building capability in primary / community care

The success of the revised pathways depends on the capabilities and engagement of the primary (and community) sector. There was a general sense amongst interviewees that engaging primary care has presented a significant challenge to the SP, and that impact in terms of culture change has not yet been seen. This had led to some delays in the recovery package being fully implemented.

Interviewees reflected on a number of reasons for the difficulty in engaging the primary care sector:

- **Pressures on capacity** – We interviewed four HCPs in primary care. These interviewees reflected on how the current national context of healthcare is placing a high burden on primary care “asking them to do more and more”, meaning that GPs in particular are “keep(ing) their heads down doing regular GP work rather than being ‘clued in’ to what’s going on in the world.” The number of patients being discharged on the revised pathways is also still relatively very small. This makes engagement less likely within the context of other external pressures.

  Despite this, interviewees in primary care all thought that the revised pathways were the “right thing to do,” both in terms of patient experience but also in terms of HCPs who ultimately find job satisfaction in doing their job “properly rather than a tick box”, where they are enabled to build a relationship with their patients and help them to support needs more effectively: “for the first time in many years I felt like I was doing some proper nursing… being led by the patients rather than led by QOF points.”

- **Anxiety over supporting cancer survivors/patients** – Some stakeholders reflected on being more involved in cancer care and support could be “anxiety building” for primary care HCPs, since they have not historically played this role. This was reflected by one of the primary care HCPs we spoke to: “People feel that they have to tread carefully. It's a difficult area in general practice. You are nervous of what you say in case the person hasn't taken it on board.” Another primary HCP disagreed with this however, stating that there was no anxiety in relation to the additional role placed on them by the revised pathways, since this was part of their job anyway (e.g. conducting reviews for other LTCs).

- **Misunderstanding of the primary care role** – Although all GP practices in the city have been signed up to the LCS, and efforts have been made to support primary care engagement with what is required of their role, (e.g. through the 1-2-1 service), there has been indication that the role of primary care has still not been universally understood. This shows how culture change at a system-wide level is yet to happen. An audit conducted by the CCG showed that some practices haven’t had any patients through the revised pathways yet (which is a possible reality given the early stage of the pathways); some had identified all their colorectal patients (including those still in treatment); and others had either misunderstood the service or thought they had not signed up for it. One interviewee reflected that this confusion might have been caused by the service being part of a ‘basket’ of services. Further work to clarify the role of primary care will therefore be required, since this currently presents a potential risk for efforts to embed the revised pathways, and by extension a potential risk to patient care.

Overall, interviewees thought that some progress had been made in engaging primary care. They reflected that improvements had been made in embedding elements of the recovery package in primary care (these will be explored in Sections 3.2.1-3.2.2 below). Success factors cited included the role of the project and programme leads, as well as the 1-2-1 service. These posts have been crucial in communicating the ‘message’ of the SP, however there is some concern over the sustainability of the changes made (and the impact of these in terms of longer term culture change), once these roles are no longer in place (although expansion of the 1-2-1 role into a primary care development nurse role is being explored):
"...[I don't know if they are] embedded enough such that when we take out the dedicated resource and support that it won't just go back to 'business as usual.'"

The remainder of this section presents findings in relation to specific elements of the recovery package – the TS and the CCR – which have implications for the primary/community sectors.

### 3.2.1 Treatment summaries are a crucial conduit for information between secondary and primary care

The TS is part of the recovery package and represents the interface between secondary and primary care, providing a snapshot of the patient’s journey. It is sent to GPs (via NHS mail) at the point of discharge from secondary care. It functions to inform them of any lasting effects of treatment, and to support signposting. The need for the TS was demonstrated by: "a recognition that letters from secondary care clinicians to GPs were of variable quality and did not always contain sufficient detail to facilitate optimal care and monitoring by primary care teams."  

Originally four trigger points were envisaged for the TS. The decision to use discharge from secondary care as the single trigger point was taken for pragmatic reasons, and for the way in which this supported the revised pathways and the goal to improve communication between both sectors. Our interviews with primary care HCPs indicate that the TS is valued since communication between primary and secondary care is crucial to improving coordinated care for patients.

The TS took some time to develop: all stakeholders (including GPs; specialist colorectal cancer clinical teams; and STH information management staff) were involved in the process, and having a TS which was straightforward to complete was challenging. Involvement of stakeholders was also reported to have been initially challenging – in particular in relation to persuading HCPs of the clinical merits of the TS. One interviewee reported that the project lead was instrumental in making the TS clinically relevant, supported by relevant colorectal data.

IT challenges were reported by a number of interviewees, mainly in terms of the barrier represented by systems not "talking" to each other. This meant that staff had to manually populate fields: "We recognised that we couldn’t just hit a button and all the relevant information would be pulled together from the relevant sources. People would need to input quite a bit of the data. Because we focused on a specific point – the transfer back into primary care – that fitted with the nurse-led service and we were able to achieve some success because it was within the nurses’ remit, rather than us having to go to each and every clinician”.

Given the number of challenges associated with implementing the TS a number of interviewees identified its establishment and use as a significant outcome in itself. One interviewee reflected on the “big achievement” of ensuring that the STH information system (infoflex) automatically populates some fields, and that it is embedded – although there are indications that some GP practices have still not engaged with them. Since universal engagement with the TS – which represents the interface between secondary and primary care – has not been seen, thus far impact in terms of system-wide culture change has been limited.

The internal evaluation of the TS states that all patients discharged into primary care had received a copy of the TS by post. In terms of completion, the evaluation reports that colorectal nurse practitioners take 2-3 minutes to complete each TS; a similar length of time taken to dictate a letter (the previous process), suggesting an improvement in consistency of communication at no additional time cost. Interviewees also noted that learning generated from the process could be transferred to other cancers – i.e. that there is now a universal template for the TS.

3.2.2 Implementation of the CCR is still at an early stage

The CCR – a component of the recovery package – is a review of the care plan, extending the holistic approach taken in the HNA and supported by the TS. It ensures that additional issues highlighted in the TS are taken account of, and that patients are appropriately signposted to additional support where required.

There is an important distinction between the CCR implemented by the project, and the CCR under the national QIPP scheme, linked to the QOF. The latter is a review which takes place within six months of diagnosis. The CCR implemented by the project is conducted in follow-up care (at six months after discharge from secondary care) and has been commissioned as part of the LCS. Whilst similar in content, it benefits from additional support in the form of the TS and the education and awareness work (see Section 3.2.4), which aims to ensure the review is conducted appropriately rather than as a ‘tick box’ exercise.

Support for the CCR has also been built in, in the form of a template linked to guidance and resources, and a signposting toolkit contained on the PRESS portal. The 1-2-1 project has also provided direct support to practices in conducting the CCR (see Section 3.2.3).

An audit conducted by the CCG has been conducted to gather data on the number of CCRs which have been conducted, and the length and timing of the appointment to conduct it. Some interviewees stated that this audit has raised concerns, with numbers being lower than expected and some practices stating that they had not been aware of the changes (again showing that culture change in primary care has not yet taken place). This finding mirrors general evidence on the implementation of the national QOF CCR: variable practice has been found in research conducted by the Macmillan primary care community. Implications for the CCR not being conducted as expected are that patients would lack routes into more holistic support, may feel that their needs are not reflected, and may miss out on opportunities for emotional support provided by primary care HCPs.

Evaluation findings indicate that it is still too early to determine outcomes of the CCR. Primary care HCPs who were interviewed had no personal experience of conducting the CCR with colorectal cancer patients. Some interviewees more generally commented on the length of time that patients had been on the revised pathway. Numbers who had been on the pathways for longer than six months were low at the time that these interviews took place. These interviewees therefore advised caution in drawing any conclusions at this stage, on how engaged primary care is with the project.

One HCP we spoke to had had experience of conducting the CCR with breast cancer patients however. She commented on the positive benefits of the process for these patients: "Patients really seem to value the opportunity to explore any issues that they feel the need to. Patients are very well looked after by the breast care nurses and have a lot covered – but still appreciate coming in to just chat… it’s nice for them to have someone to contact in general practice and a lot of it is emotional support… they have all left saying thank you so much it’s really good to have someone to talk to".

Outcomes reported in the 1-2-1 project local evaluation also provide some insight. Although the evidence here refers to a sample which contains a minority of colorectal patients, and is in relation to the QOF CCR conducted with newly diagnosed patients, the following outcomes may be equally relevant to the local CCR in primary care follow-up:

- The CCR (QOF) took an average of 58 minutes to complete, with an average of 34.6 minutes per patient being spent on administrative tasks;
- Patients evaluated the CCR as useful, and said that they thought the GP practice team was important in their cancer care; and

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30 Ibid.
32 Coy, J. (2015). Macmillan 1-2-1 support service pilot: results of the questionnaire sent to patients
Practice staff findings were mixed, with over half saying they had used the CCR template, but three quarters saying that they were unaware of the toolkit.

3.2.3 The Sheffield 1-2-1 support service pilot has supported primary care delivery of holistic care

This service contributed to the survivorship work in Sheffield through support provided by a nurse who was able to act as a ‘change agent’ for holistic care.

Over 50% of GP practices (46 out of 88) signed up for support from this project, with 10 newly diagnosed colorectal patients being referred to the Macmillan Primary Care Nurse. Referrals have been lower than anticipated; the service is also resource intensive so is not likely to be sustained in its current form in the long run. Plans are in place however to continue the work started as part of this project, in order to continue to support primary care in survivorship.

A local evaluation of the pilot was conducted, based on data from the period 1st January-30th November 2014. Outputs and outcomes reported in this included the following:

- 10 colorectal patients were referred to the service, all these were aged over 50 years.
- Taking colorectal and breast patients together (total = 34), there were an average of 3.7 referrals made per patient to support agencies/services. The majority of these were to the Cavendish Cancer Centre and the Cancer Support Centre at Weston Park Hospital, followed by Age UK. One referral was made to the Sheffield bowel cancer support group.
- Staff from half of the practices taking place stated that the pilot had helped improve care and support for cancer patients.

Additional outcomes reported by interviewees included:

- Additional temporary capacity. One primary care HCP we interviewed commented on the value of this role: “Thanks to [the nurse] our patients have benefitted immensely and their feedback has been fantastic. As a GP seeing patients with only 10 minutes, having [the nurse] to signpost patients to and follow up after her review, allows me to use my limited consulting minutes much more effectively. Her help and input also acts as support for me when I fall short in my knowledge of local resources etc.”
- Raised awareness of holistic cancer care in primary care: “The going out and working with the practices, which [nurse] has been doing even if she hasn’t had a referral, has raised knowledge and awareness.” This shows that although widespread culture change towards more holistic care in primary care may not yet have taken place, there is potential for this to happen in the next phase of the programme.

3.2.4 Staff development and training has been important to embed changed practice

The project has supported the revised pathways by offering a number of development and training opportunities to both secondary and primary/community care staff, as well as to staff from broader support agencies in both the public and voluntary sectors. The aim of this development work was to change the established culture of care through raising awareness of cancer survivorship; through increasing knowledge of the revised pathways and local resources; and through upskilling HCPs in person-centred techniques which lend themselves to holistic care.

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36 Ibid.
The project’s evaluation report and interviewees described the various training packages and associated outcomes which have been implemented:

- **Motivational Interviewing** – This was delivered in partnership with Sheffield Hallam University and was open to staff from any field (health and social care, voluntary sector) who work in LTCs. MI is an approach to working with people in a person-centred way, emphasising language, acceptance and being non-judgemental. The approach seeks to help people achieve behavioural and attitudinal change. Using MI for the survivorship project enabled it to be aligned with work with LTCs more broadly across Sheffield, since this has been the approach adopted here. Local evaluation findings showed that the course was highly rated, with 97% (31 participants) of respondents saying that the extent to which the course developed knowledge and understanding was either excellent or good. Reflections from one interviewee also included that MI benefits staff; they are less likely to experience burnout as they do less ‘work’ by passing on ownership to patients.

- **Cancer awareness training** – This course was delivered by a Macmillan trainer, and was aimed at non-qualified staff, providing an overview of the cancer pathway from diagnosis and treatment to survivorship. All those attending (21 participants) were highly satisfied with the course, stating that it was highly relevant to their role.

- **Protected Learning Initiative (PLI)** – ‘Cancer in the future’ was delivered during this mandatory study time for GPs and practice nurses. 265 people attended, with GPs making up 72% of participants, and nurse practitioners and practice nurses making up 20%. The event included four keynote speakers (consultants and clinical psychologist); a workshop for practice and community nurses; and information stalls to raise awareness of local support services. All those who completed evaluation forms stated that the PLI had increased their knowledge of the role of primary care in cancer management; 91% said that it was relevant to their clinical work; and 73% said that it would change how they worked.

- **Living with and beyond cancer** – This was a two-day course for primary care nurses which was run in partnership with The University of Sheffield. It has been sustained as a CPD component for nurses. The course was evaluated using a pre/post design. Confidence about taking a supportive role for patients increased from 31% to 75% after the course (15 nurses attended).

- **Listening and responding** – This was delivered by a Macmillan trainer for practice clerical staff. It was a half-day course as part of the PLI event. It aimed to increase confidence in liaising with PABC. Evaluation findings showed that the majority of responders (49 out of 53 course participants) rated the course as either excellent or good.

### 3.3 Developing more holistic packages of support for PABC

The Sheffield project has implemented new pathways which are changing practice in and between secondary and primary/community care. When designing the project there was also an appreciation of the need to build in/work better with additional support services. This would allow for ‘holistic’ care to be delivered more effectively. We describe below the implementation and impact of a number of local services/projects which support the survivorship ethos, and have therefore been included in the signposting element of the revised pathways.

#### 3.3.1 The CALM course was trialled and discontinued

The CALM course was developed in partnership with the Cancer Support Centre. It was originally a six week course (then reduced to four weeks based on feedback) adapted specifically for colorectal cancer. It was designed to support PABC confidence and knowledge for self-management.

The course was trialled in various ways in response to ongoing feedback from attendees. It was originally designed to be delivered at the point of transition from secondary to primary...
care, but was then delivered at two earlier time-points (midway through secondary care follow-up, immediately following treatment). The general consensus from both interviewees and the local evaluation is that take-up for the course was too low. The local evaluation shows that for a total of four courses planned, only two were delivered to a total of eight PABC.\textsuperscript{38}

Low take up was explained primarily as a feature of the support already delivered from the colorectal nursing team. The local evaluation showed that many of the participants said that they were already aware of the information received and that it might have been better to have the course earlier in the pathway\textsuperscript{39}. Other issues explored by one of the interviewees included that a mixed sex group might act as a barrier, since many of the late effects of colorectal cancer can be of a personal nature. Another comment was made in relation to the location of the cancer Support Centre, and that this being on the hospital site might act as a deterrent in its contradiction of the ‘moving on’ message. Indeed the local evaluation found that many of those invited who refused gave the reason for refusal as not wanting to be reminded of their having had cancer\textsuperscript{40}.

Despite low numbers there were some positive outcomes reported by those who attended. These included the way in which the course supported the expression of feelings and sharing of experiences within the group. Pre and post course wellbeing scores using the MYCAW (Measure Yourself Concerns and Wellbeing) tool showed no positive change.\textsuperscript{41}

As a result of the low take-up, CALM has been discontinued for colorectal cancer, although it may be utilised in future for other tumour sites. Patients who want to take part in a group course will now be referred to the ‘Positive About Life’ course, which is a positively evaluated generic course for all tumour groups, run by the Cancer Support Centre for a number of years\textsuperscript{42}.

\subsection*{3.3.2 The ‘working through cancer’ project has supported a small number of colorectal patients}

This project is built around the NCSI’s three-tier model of work support for PABC (see Figure 3.1). Thus far it has supported PABC at Levels 1 and 2, although there are plans to extend this support to Level 3. Interviewees suggested that expected outcomes of the project would be in terms of the support being more accessible, rather than in terms of getting people back to work sooner. To date, the number of colorectal patients supported by the service is limited; two out of 33 patients seen by SOHAS having had/living with colorectal cancer (between April-December 2014).\textsuperscript{43} This is likely to reflect colorectal cancer’s prevalence and patient age profile.

\begin{footnotesize}
\begin{enumerate}
\item CALM evaluation report (2014).
\item Ibid.
\item Ibid.
\item Ibid.
\item CALM evaluations received from the session on 15\textsuperscript{th} January 2014; MYCAW from 15\textsuperscript{th} July 2014.
\item Ibid.
\end{enumerate}
\end{footnotesize}
Level 1 – All patients who are in work or have the potential to work should be asked about their employment, and receive information and signposting.

Level 2 - People with specific concerns or worries should be provided with resources to support self-management.

Level 3 - The smaller subset of people who have complex needs should be referred to a vocational rehabilitation service for specialist support.

Source: Sheffield Transformational Survivorship Project: Interim End of Project Report

The project is still at an early stage and will run until 2016. Further developments planned include the following:

- Working with employers so that they can better support PABC, and promote a cancer specific work policy;
- Implementation of a workplace wellbeing charter – quality standards for assessing/improving health and wellbeing of the workforce; and
- Continuing to seek funding for Level 3 support – people with complex needs being supported via referral to a vocational rehabilitation service for specialist support. This service is not currently available in Sheffield, and it is expected that should it be funded it will be open to all cancer groups/LTCs.

3.3.3 Links into physical activity are being made, but are at an early stage

At the time of interviewing the local authority based physical activity project had not yet started. Findings on implementation and outcomes can therefore not be reported. In reflecting on the need for this project one interviewee referred to the importance of lifestyle support in providing holistic care, and to the links of reducing recurrence: “We’ve known for a long time that physical activity is something that patients should engage with...the problem is that it’s not embedded and is seen as an add-on. So this is about a more holistic view of patients’ programme of care – about what will reduce the risk of secondary occurrence.”

Expected outcomes were discussed mainly in terms of increasing physical activity levels – by sustaining 30 minutes of exercise a week. One interviewee discussed how those with higher need (i.e. patients with LTCs) tend to have a much higher dropout rate.

The value of Macmillan involvement was also reflected on, with interviewees suggesting that this would enable higher impact of both the project, but also future partnerships between the local authority based service and the health sector. “We’ll have a much greater impact in the health sector coming through Macmillan, they have some standing and are recognisable, we’re very community based so getting into that sector is difficult. We’ll help them in the community and they’ll help us in the health sector. The links will continue after the project.”
4 Early PABC experiences of the revised pathways in Sheffield

Section summary:
Findings from the peer research indicate that the colorectal team in secondary care is very well regarded. For some of the interviewees this has led to some apprehension about being discharged into primary care follow-up. Feelings about being seen in primary care are therefore mixed. Relationships with GPs are important. Those who are worried about being transferred do not necessarily have a negative relationship with their GP. However those who are happy to be discharged are reassured by having a positive relationship with their GP.

This section summarises findings from the peer research. The revised pathways are still at an early stage of implementation and the analysis reflects this. The section is structured around different points of the system described by interviewees: secondary care, primary care, and support received in the community, and through the VCS. Findings described are supported by quotes from the interviews throughout.

4.1 Interviewees were unanimously positive about secondary care

Peer research findings showed that interviewees were unanimously positive about the care and support received from the colorectal team. Discussions related to care from diagnosis through to treatment and follow-up. Many of the interviewees commented that the consultants were very good in their care through their treatment, and that the nurse follow-up was a positive experience:

“He speaks English instead of you know doctor’s talk, if you know what I mean, you know how they say big words and that!”

“I couldn’t believe how easy it was to talk to the nurse and the information they gave me, how it relaxed me actually.”

“I had a lot of support I mean while I was at hospital, under the hospital everything was really good…very good doctors I felt. And nurses as well.”

The exception to this positive experience was in relation to hospital admissions following surgical procedures. Particular issues were reported in terms of dietary needs not being well catered for (e.g. a diabetic diet), and the physical environment of busy wards.

4.2 Those who attended the HW day found it helpful

A small number of interviewees had attended the HW day, and had found this helpful. The quote below illustrates how one interviewee was able to use advice and information from the day in order to self-manage eating behaviour and weight:

“They told me to graze through the day and we found that, for the most part, really helpful because I didn’t want to put any weight on, I’m big enough now and I didn’t want to get oversized again…and there was exercises…I chose the exercise class and healthy eating class because even with this you’ve still got to eat healthy haven’t you…so yeah, I found it enormously helpful.”

Some interviewees who did not attend recalled that they had been invited. One interviewee had signed up to attend but then forgot; she commented that there was no reminder sent. Another recalled being invited but hadn’t attended for various reasons, including late effects of colorectal cancer:

“Well first of all it was Christmas time, so I thought a lot of things would be closed anyway and then after that I was sort of, quite busy - life took over. I did spend time going to my GP a
bit because I found problems with the toilet afterwards, so I was quite busy with all that as well."

4.3 In general, interviewees felt well prepared for discharge

The majority of interviewees were well informed about their pathway, and described this in terms of the length of follow up in secondary and primary care respectively. They also described that they had received information both in the form of leaflets/booklets, and also in verbal form.

Some interviewees stated that they were confident in recognising signs and symptoms of recurrence, and were reassured by the contact card they were given at the point of discharge – which allowed them to call back to speak to a nurse if they wished. The nurse could then arrange for rapid access back into secondary care if there was a clinical need for this. A minority of interviewees were more reluctant to call back in because they did not want to ‘bother’ busy nurses since they had been ‘discharged’:

“I’ve been discharged and I feel that it’s extra to the work that they will have to do, because they’ve got so many patients to look after haven’t they and then somebody from way back comes and wants attention, they can’t do it can they, they’re stretched enough, them nurses aren’t they.”

Some of the patients recalled receiving the treatment summary and were aware that the GP had also been sent a copy. Others were less clear that GPs had been informed of their treatment whilst under secondary care, and had found that they had to chase up processes which they had considered ‘automatic’:

“I think one of the things about being in hospital care is you’re very clear about when your next appointment is...my concern [on being discharged] was whether it would all be automatically triggered from the next blood test, that I would hear from my surgery and I haven’t done.”

“I’ve been once for the blood test and I’m due again in December, but I understand that I’ve got to ring them, they’re not informing me it’ll come in.”

Many (although not all) of the interviewees recognised that they had had a care plan. Whilst some were able to identify the language of a ‘care plan’, others described this in terms of an information booklet they were given. Care planning was therefore generally seen as information giving, although interviewees recognised this within the context of good quality care from nursing staff:

“Yes, yes I got a care plan, I knew exactly when I was going to come back for tests and what was going to happen.”

“I think yes, there was a booklet about how they were going to manage it afterwards to follow, yes, which I read with interest and I’ve done everything I was supposed to do.”

“I got a booklet with all that I could eat and all that I couldn’t eat.”

“Yes I received a care plan...[names nurse] she is very kind, very devoted to her job and she is very attentive, listening to you because she understands what you’re going through and she was always there with the care plan and she always gave me leaflets of what to do or ‘call if you need to’.”

Interviewees were less clear about the HNA and did not typically identify it as a discrete intervention – despite having been mailed the HNA tool before appointments. However, one interviewee did relay being asked about their needs during their contacts with the colorectal nursing team:

“I know I filled in various forms and I know they’ve sent me lots of letters saying did I want to come to this talk or that talk, but I have a massive circle of friends and I feel I didn’t need that other support at the time, I know it’s there if I need it, which I’m grateful for.”
The implications of this finding are that the HNA may need to be used differently, for example by collaborative use of the tool in consultations rather than a mailout. Recognition on the patient’s part of the HNA as a discrete intervention is probably a lesser concern, as long as patients recognise that their holistic needs have been taken account of and that they have been signposted appropriately.

Most interviewees thought that holistic needs had been well catered for in secondary care. Signposting to other services was commonly described in terms of information they were given in written form. For example, a number of interviewees identified leaflets and letters they were given about the CALM course, the HW day, and the Cavendish Centre.

There may however also be scope for more active or ‘supported’ signposting, where patients are actively guided to take up services they are signposted to, based on individual confidence to self-manage, (e.g. through active referral processes/assisting with telephone calls/identifying named contacts). People have different capabilities for navigating a wide array of support services across different sectors. One interviewee commented on her lack of knowledge in this respect:

“I don’t really know about these places, but yeah I’m sure if I was to ask or if I looked back through my information it’s probably there.”

There are implications here for how going forward the SP in Sheffield works with broader community services. Community mapping and engagement with key organisations referred to would be particular avenues to explore (see section 6.1 on related work in Doncaster).

**Feelings about discharge into primary care were mixed**

For many interviewees being discharged into primary care caused some apprehension. This was often explained in terms of the excellent care they received whilst under secondary care follow-up and consequent uncertainty in leaving it. Having confidence in GPs did not necessarily lessen this feeling.

This finding may in part be explained by the nature of support and how this was perceived to be different in secondary and primary care. Interviewees described their experience of secondary care support in terms of more intensive (e.g. more frequent and longer appointments) and specialist (i.e. knowledge and experience of colorectal cancer) inputs. Perhaps counterintuitively, secondary care support was also more likely to be described as holistic in accounting for additional needs, whereas primary care support was seen in more ‘medicalised’ terms (see Section 4.4 below). Interviewees related informal emotional support in particular to their experience of secondary care, and it is important to consider the implications for patients who experience the loss of this ‘hospital touch’.

The following quotes show how the change to primary care follow-up evoked these feelings for different interviewees:

“Although I've got a good doctor...I just think: would I get the same value of care that I was getting at the hospital...[I was] apprehensive really, because I'd been treated so well at the hospital, I'm thinking will I get the same sort of treatment from my doctor, like, you know, and they're the people who are experienced in aftercare for cancer patients and I'm thinking, you know, as good as the doctors are at my surgery...I just wondered if I'd get the same sort of follow up.”

“At the time I think I sort of felt a little bit cut off because I'd got on very well with the nurses and it was sort of every three months...and I quite looked forward to going because you could talk about anything to them and you'd get a straightforward answer.”

“The only thing I do wish is it was still five years at the hospital because you've lost – to me I lost my lifeline a little bit – but I feel as if I'm ok to be discharged to my GP but you feel as if you've lost out because you've lost that hospital touch.”

“They just said that's it you're going to have your blood tests at the surgery, your care is under the GP now. I just felt out on a limb really. I thought: what do I do now? You know, so I made an appointment to go and see my doctor but I didn't find him very helpful really.”
A few of the interviewees stated that they were happy to be discharged into primary care, and this was largely explained by having confidence in their GP; having inputs from district/community nursing; and by being well informed by the colorectal team from an early stage in the pathway:

“No, I was fine because my GP is quite good, in fact the whole practice is quite good, and I didn’t really feel I needed anything, because I was also seeing the incontinence nurse from the community, so I felt like I was being taken care of.”

“I don’t think I felt anything really because I knew it was coming. One of the nurses that I’d seen earlier had explained to me that this was going to happen...I was expecting it anyway so I didn’t really think a great deal about it.”

One interviewee talked about how being under primary care follow up ‘made sense’ since it aligned with the GP role in other conditions:

“It was general and ongoing from my GP. He was always checking my blood pressure and all sorts of things and insisted that I went on a regular basis, and I was also under the doctor for my diabetes and things like that.”

An important aspect of the transition from secondary to primary care is the degree to which patients feel their care has been integrated or ‘seamless’. A small number of interviewees reflected on how integrated their care was in general (rather than in follow-up specifically), with findings suggesting that patient experience was variable:

“It wasn’t sort of bits here, there and everywhere...it seemed to gel together.”

“When I came out of hospital, they said they’d send a form to the surgery, and when we had to send for them again she said ‘we didn’t even know you’d come out of hospital.’ So who’s at fault there, I don’t know, whether they’d not looked at it or whether the hospital hadn’t sent it.”

4.4 Primary care follow up is still at an early stage; relationships are important

Interviewees’ experiences reflected the relatively early stage of the Sheffield project, in that they were still at an early point in their primary care follow-up. Interviews took place between November 2014 and January 2015, and the first CEA tests would have been due six months after they were discharged (September 2015 at the earliest). As such, many of the interviewees described that they had not yet received any follow-up at all in primary care.

An important finding is that historic experiences and relationships with GPs affected experiences of follow up primary care. Whilst many interviewees described positive long standing relationships with their GP practices, there were others who had negative experiences either specific to colorectal follow-up, or more generally.

On seeing GP for colorectal follow-up: “He’s a lovely GP, he’s got a lovely bedside manner, he makes you feel very very special and I feel as if that’s the person I want to see, and as far as I’m concerned that’s the person I will see.”

On historic bad relationship with GP: “I walked in and he was sat down, never got up and I explained well as soon as I said ‘the physio said I need an MRI’ he just erupted, ‘who said that!?’ it was absolutely horrible...and I wouldn’t go to the doctor’s after that.”

Early detection and follow-up referrals for ongoing tests were indicators of trust in GPs for interviewees:

“They knew exactly what it was as soon as I started talking to him without him doing any tests on me, which I thought was brilliant of him, how he picked up on just that.”

Follow-up under primary care had generally been understood in medical terms rather than in holistic terms, with most interviewees referring to CEA blood testing as synonymous to follow-up in primary care. None of the interviewees had received, or knew that they were due to receive, a CCR. Whilst this might be an indication of the early stage of the pathways, it is also possible that the pathways have not been understood in primary care as supporting
patients in additional and non-medical needs. There were some interviewees for example who indicated that emotional support was lacking, and would have been appreciated – even if this was in the form of a simple ‘how are you?’:

“I didn’t really know what aftercare would be apart from the blood tests...I thought they might have said, one of them might have said something when I’d like this chest infection but no it was never mentioned...it would have been nice if they’d have said ‘how are you feeling?’ or something like that just to know that they do know what’s happened to you.”

“Just somebody to listen really, to feel that you can say ‘look I’m feeling this and that and the other’...like they do in diabetes, I have to go every six months and talk about things, they tell me how I’m doing and then ‘have you any concerns?’, that sort of thing really.”

The two quotes above also illustrate the importance of holistic care across conditions; there is scope for example for approaching the CCR holistically. Many interviewees talked about their co-morbidities (which sometimes took precedence over colorectal issues); they wanted consistency and did not see themselves in terms of isolated conditions.

Peer research findings indicate that when in secondary care patients are accustomed to being informed about what to expect in the pathway. Their expectation is that this is what will happen once they are discharged into primary care follow-up. There do not however appear to be consistent processes in place for this yet in primary care. This has important implications for the patient experience of transition, especially in light of the findings reported above in relation to some patients feeling transition anxiety due to the different types of support experienced in secondary and primary care, (see Section 4.3). In particular interviewees commented that proactive contact from practices would be helpful in clarifying follow-up processes:

“Nobody's got in touch with me and said you've been transferred to us now...that would be something [a recommendation for improvement] - if the doctor got in touch with me and told me now that I'd been transferred from the hospital to their care...because it would acknowledge that it has been transferred and it's been properly registered that this treatment will be administered from them now rather than the hospital.”

“Well I did wonder because nobody mentioned it to me at the doctor's.”

“I don't know what happens because I've not had one since from the doctor, I presume the doctor gets in touch with me, I don't know”.

“And he says ‘well you just make an appointment and come and have it done’, but you know I just didn’t know what to expect basically.”

The number of interviewees who had received a CEA blood test at the time of interviewing was limited. One interviewee commented how regular testing reassured him that he was being monitored effectively. Another commented on the lack of awareness when she was tested:

“I'm supposed to have them every three months which I've been having, twice my readings have been slightly up so he's keeping a closer eye on me, so I'm having them every month at the moment. And then no doubt if they go higher then - I don't know at what level - they'll send me back to the hospital. They seem to fluctuate, one month they're up one month they're down, so it's great they are keeping a close watch.”

“I mean the nurse said to me what are you having these blood tests for? And I said well I've had bowel cancer and she didn't even know what they were for.”

4.5 Interviewees discussed the non-medical support they had utilised

Interviewees were asked to discuss their experiences of additional, non-medical support. Many tended to think of ‘emotional support’ as more formalised support; the majority stated that they had been offered but did not want emotional support from external agencies – even though through the course of the interviews many did discuss in detail the emotional element
of their experience with cancer, and their need for informal emotional support from HCPs (see for example Section 4.3).

There was some indication from our findings that psychological/emotional support needs might be more salient after treatment has ended:

“Well it happened so quickly and I saw a consultant and he said to me ‘it’s an emergency, I’ve got a spare slot tomorrow’...I ended up in intensive care I don’t know how many weeks later...so I think that’s why I was out of action for so long I felt that I didn’t feel anything psychologically.”

“I didn’t really want to talk about it at first, but I feel I can do now, but I don’t know if it’s denial or what it is, but I didn’t really want to go into it with a lot of strangers.”

However once out of treatment, some patients may still not want to consider taking up formal emotional support. For a few interviewees, making use of non-medical support was linked to the process of ‘moving on’:

“I think I’m like most people in my position, I’ve sort of dismissed it [formal emotional support], it’s like that’s nothing to do with me now, I’m better and I’m just getting on with my life.”

One interviewee described how additional support wasn’t needed because she was happy with the support she had had from the colorectal team:

“No, not really because I didn’t really have any [additional needs]. I felt good because I felt like things were being followed up and that somebody was keeping an eye on me, so I felt that was the only support I really needed, to know there was somebody there if I needed them.”

Some interviewees described other sources of emotional support which they had made use of. Social networks were integral to the positive experiences that interviewees described. In particular spouses/partners; family and friends; neighbours; and the church were valued greatly.

Two of the interviewees had attended the CALM course run by the cancer Support Centre. One of these commented how although it had been very good she did not ‘need’ the additional support offered through it since she had a strong support network in her own family:

“Very good. There was only two [of us] and the other girl was a lot younger and she asked all the ins and outs whereas I just sat and listen. I enjoyed listening to her...they covered all sorts. Nutrition, health, what to look for next...and they said if you want support you can get it...but I didn’t think I needed it because of my family.”

When asked about support that was offered to families and carers, many interviewees responded that this had not been offered at all. A small number said it had been offered, but it was not needed. Support for families and carers was mainly understood in terms of information about the patient, rather than as support for their own emotional, practical, or social needs:

“I just used to feed off the information that [names patient] got and personally I thought everything about it was perfect...and they gave you so much confidence too.”

The Sheffield bowel cancer support group was also identified as a source of support by a few interviewees. Whilst one interviewee had not found this helpful (“It wasn’t for me”) others had found it valuable for the information given there, and for the value of talking to people in similar situations:

“This group that we go to, I do see people, and it’s all bowel cancer, it’s no other cancer, you know, and you can talk, you know somebody might say ‘ooh do you know since I’ve had the operation or the chemotherapy, I’ve got so and so.’ And I think that’s me, so then you say ‘well mine’s same as that, you know, I’ve done that and I do find that helpful.’ "
Reflections on the value of peer research

Our experience of using peer research highlighted a number of benefits. These included benefits to the evaluation; benefits for patients being interviewed; and benefits for the peer researchers themselves.

Feedback from the ICF trainer reflected the value brought to the evaluation by the peer research:

“The peer researchers were a privilege and a pleasure to work with. Their approach to the whole process – from participating in the training, to setting up interviews and carrying them out - demonstrated their commitment and skill. They added real value to the evaluation and I learnt an enormous amount from them.”

Benefits to the evaluation are mainly around the richer data that is gathered from an approach where interviewees speak to ‘peers’ who have also been affected by cancer. The trade-off between using peer researchers or the evaluation team to conduct these interviews – the latter being a less resource-intensive approach – is made with this in mind.

Feedback from the peer researchers (see below) indicated how interviewees appreciated being interviewed by peers. This is a valuable outcome in terms of ethical research with potentially vulnerable people. It is also valuable for the evaluation itself, in terms of the data gathered – if interviewees are able to establish a stronger rapport with interviewers then the likelihood of them being more open and candid in sharing their views is greater.

Peer researcher experience

Peer researchers described how they had greatly valued the opportunity to participate in this evaluation. They were keen to be involved throughout the process and worked hard to ensure they had sufficient knowledge (of the programme and interview skills) in order to carry out the interviews.

Peer researchers discussed how the patients they interviewed found it very rewarding to be interviewed by people who had been in similar situations to them. The quotes below are taken from peer researcher feedback on the process of being involved in the research:

“People can feel more comfortable with someone who has a real connection with their particular issues.”

“I would applaud the decision to have peer evaluation of the project rather than having the interviews with patients undertaken by researchers. I know the patients appreciated that too. They specifically commented on the fact that they felt more able to talk freely to someone else who would understand what they had been through.”

“I am really looking forward to seeing the report. Thanks for all your hard work [names ICF trainer]. It has been a real pleasure working with you.”

Finally, peer researchers also made some recommendations based on their experiences in the research:

- Patients should be helped to better understand the rationale for early discharge. In particular that this is not simply about saving money. Patients should be helped to understand the low detection rate of recurrence of cancer at hospital clinic visits.
- A further evaluation at a year or six months might yield useful additional information; it will provide information about sustained impact of the new pathways.
5 Economic analysis of the revised pathways in Sheffield

Section summary:
It is early in the implementation of the revised pathway. This limits economic analysis to modelling costs ‘as they are likely to be’, rather than ‘as they are’. Lack of evidence on benefits also restricts analysis. A cost-comparison is therefore presented, examining the ‘old’ and the ‘new’ pathways. The results suggest that the new pathway is broadly cost-neutral, albeit with changes in the distribution of these costs (e.g. between different parts of the NHS and voluntary sector services). More research is needed to verify these results and to generate further information on the patient benefits resulting.

This section presents the economic analysis of the new colorectal cancer care pathway. The approach selected was a cost comparison analysis. Results are presented and a sensitivity analysis is included.

5.1 Method
The approach chosen for the economic analysis was a cost comparison analysis of the ‘old’ and ‘new’ care pathway. This involved estimating the cost of providing support to a cohort under the old care pathway, and comparing this with an estimated cost of supporting the same cohort of patients on the new care pathways. The method and the scope of the study were selected due to resource and evidence constraints, however the results provided are strong enough for indicative analysis of the cost of the care pathways.

In considering what follows, it is important to note that:

- A full cohort of patients has not been supported for the full length of time covered by the new care pathways. Therefore the method presents modelled results of the intended costs of the care pathways rather than an audit of costs incurred by the care pathways;

- The purpose of the exercise is not to provide an accurate analysis of the absolute costs (e.g. to commissioners or providers) of providing these pathways. The costs provided here cannot be used as the basis for a full costing of the pathways concerned. Rather, it is the relative difference between the old and new pathway that is of interest. This means that the costs provided below may be (in fact, are almost certain to be) wrong in absolute terms, but this does not affect the main conclusions of the analysis;

- The methodology focusses on comparing the ongoing costs of providing care on the old and new care pathways. It does not include the costs associated with developing or implementing the new care pathway; and

- The analysis focuses solely on cost. This leaves aside the vital question of benefit (e.g. improvements in patient experience / outcomes). Evidence on the benefits of the revised pathway is presented elsewhere in this report (sections 3 and 4); overall conclusions, combining evidence on costs and benefits, are presented in the final section of the report.

5.1.1 Scope of the analysis
The economic analysis focused by:

- Geography – The cohort of patients included in the analysis was limited to Sheffield.

- Timeframe – The analysis covered a five year timeframe. This was selected because patients are formally supported on both the old and the new care pathways for this period.
- **Type of costs** – The analysis covered a broad range of costs, in order to estimate the total costs of each care pathway to all individuals and organisations involved in the care pathways. The range of costs included:
  - Costs to primary and secondary health care;
  - Costs to patients and carers, e.g. in the time spent travelling to, waiting for and having appointments with healthcare professionals;
  - Costs to the voluntary sector of providing support to patients; and
  - Costs to employers due to colorectal patients or their carers being absent through attending outpatient appointments.

- **Patients analysed** - The research focussed on the cohort of patients who have been stratified onto the new care pathway so far – 195 patients (between 1 September 2011 and 15 November 2014). There were a total of 1,506 patients diagnosed with colorectal cancer in this period, therefore 13% of all colorectal patients had been risk stratified and included in the analysis. However, 1,311 patients have been excluded from the analysis. Table 5.1 presents the reasons why categories of patients have been excluded from the analysis. Of the patients that were eligible to be stratified, 69% had been stratified (all patients who were diagnosed more than two to three years ago and who have not died).

<table>
<thead>
<tr>
<th>Patient outcome</th>
<th>Number of patients</th>
<th>Included in economic analysis</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients who have been risk stratified</td>
<td>195</td>
<td>Yes</td>
<td>These patients have been risk stratified and are being treated using the new care pathways.</td>
</tr>
<tr>
<td>Patients diagnosed more than three years ago but have not been risk stratified</td>
<td>75</td>
<td>No</td>
<td>These patients were diagnosed over three years ago and could qualify for risk stratification, but have not been stratified. Reasons include having markers on their records preventing discharge.</td>
</tr>
<tr>
<td>Patients who have died</td>
<td>438</td>
<td>No</td>
<td>It is unclear if these patients had been risk stratified and if which care pathway they were being treated on.</td>
</tr>
<tr>
<td>Patients who were diagnosed within the last two to three years</td>
<td>787</td>
<td>No</td>
<td>These patients have not yet qualified to be risk stratified, so it is unclear which care pathway they could be following. Therefore they have been excluded from the analysis.</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>No</td>
<td>This category includes patients who are not Sheffield residents, where date of treatment is missing or who had declined hospital care and were already being cared for in primary care prior to the new pathway being introduced.</td>
</tr>
<tr>
<td>Total</td>
<td>1,506</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Management Information**

### 5.1.2 Care pathways analysed

As noted above, the analysis concerns two pathways for follow-up care: the old and new care pathways:

- The old care pathway was a ‘one size fits all’ approach to follow-up, where all patients received follow up care in a secondary care setting.
The new care pathway offers tailored packages of care, and the promotion of self-management / follow-up in the community and primary care settings. The new care pathway was tailored using patient risk stratification. A patient will follow one of three main care pathways, which require a different primary / secondary care involvement. These pathways are:

1. Supported self-management (low risk); or
2. Shared care, with follow-up in primary care (medium risk); or
3. Consultant led follow-up in secondary care (high risk).

For the purposes of this analysis, the old and new pathways have been analysed as two scenarios. In the old care pathway all patients are treated and followed up in secondary care. Under the new approach, patients are assigned to one of three pathways based on their risk (see above). In the Level 3 pathway follow-up care was provided in secondary care (equivalent to the old care pathway, currently around 65% of patients according to information provided by the SP), and in pathways Levels 1-2 follow-up care was provided in varying degrees of primary care support, following 2 (colon) and 3 (rectal) years of follow-up in secondary care (35% of patients according to information provided by the SP). The care pathways are illustrated in Figure 5.1 to Figure 5.3.

5.1.3 Sources of information used

The broad range of costs considered required a similarly broad range of information in order to carry out the analysis. Annex 4 presents the sources of information used. Evidence was combined from project documentation, information from project staff and existing national data sources. The values which have been used in the calculations of the cost of the two pathways are also included in Annex 4. Some of the values presented are not used as stated in the data source (for example the value has been updated to 2014 prices). Where this was the case, the reasons why the stated value has not been used and a description of the process used to calculate the value are presented in section 5.1.4.
Figure 5.1  Summary of the old colorectal care pathway

- **Treatment** – patient then released to follow up pathway
  - Consultant follow up (6 weeks after treatment)
  - For first two years
    - Nurse follow up (quarterly)
  - CT scan (9 months after treatment)
  - CT scan (2 years after treatment)
  - After two years
    - Nurse led follow up (half-yearly)
  - After five years
    - Follow up ends

- Additional costs
  - Referral to voluntary sector
  - Primary Care
  - Cost of patient and carer time
  - Costs to employers

Secondary care pathway cost
Primary care pathway cost
Figure 5.2  Summary of the new rectal pathway

- Treatment – patient then released to follow-up pathway
- Consultant follow up (6 weeks after treatment)
- Health and Well-being event
- For first two years Nurse follow up (quarterly)
- CT scan (9 months after treatment)
- CT scan (2 years after treatment)
- In year three Nurse follow up (half yearly)
- Prior to discharge to primary care
- Holistic Needs Assessment
- GP review of treatment and follow up information
- After three years Primary care led follow up (half yearly)
- Post discharge Cancer Care Review
- After five years Follow up ends

Additional costs

- Referral to voluntary sector
- Primary Care
- Cost of patient and carer time
- Costs to employers
Figure 5.3 Summary of the new colon pathway

- Treatment – patient then released to follow-up pathway
- Consultant follow up (6 weeks after treatment)
- Health and Well-being event
- For first two years Nurse follow up (quarterly)
- CT scan (9 months after treatment)
- CT scan (2 years after treatment)
- Prior to discharge to primary care
- Holistic Needs Assessment
- GP review of treatment and follow-up information
- After two years Primary care and follow-up (half yearly)
- Post-discharge Cancer Care Review
- After five years Follow up ends

Additional costs
- Referral to voluntary sector
- Primary Care
- Cost of patient and carer time
- Costs to employers
5.1.4 Assumptions

Where possible, data described in Annex 5 were used directly in the calculations to estimate the cost of the care pathways. However, this was not always possible and some assumptions had to be used to estimate certain costs. These assumptions are presented below.

Secondary care

The values for secondary care appointments are taken directly from the National Tariff Payment System, 2014-2015. It has been assumed that:

- Treatment code 104 – Colorectal Surgery Outpatient attendance tariff has been used;
- For the follow-up appointments it has been assumed that the single professional value was the most appropriate;
- For the unit cost of a CT scan, the value for RA11Z - Computerised Tomography Scan, two areas without contrast has been used;
- The health and well-being event was happens twice a year, with each patient attending one of the events. The health and well-being event lasts for one day (five hours) and costs £2,300 per event; and
- The holistic needs assessment in the new care pathways was assumed to take place within the patients existing secondary care appointments, with no associated additional costs.

Primary Care

The values for primary care were drawn from information from the project service specification (values used as presented in the service specification) and the Personal Social Services Research Unit (2014) Unit Costs of Health and Social Care. The unit cost of GP time used was £3.30 per minute. For the GP review of treatment and follow up information it has been assumed that:

- The GP review of treatment and follow up information takes an average of 10 minutes, leading to an estimated unit cost of £33;
- The duration of the primary care appointment for Level 1 patients was 15 minutes and was assumed to be with the GP nurse, which costs £18; and
- The duration of the primary care appointment for level 2 patients was 30 minutes and was assumed to be with a combination of the GP and the GP nurse, which costs £59.

Voluntary sector

The estimation of the costs to the voluntary sector were based on evidence from the Weston Park Cancer Information and Support Centre 2012 to 2014 and the Annual Survey of Hours and Earnings (ASHE). For the costs voluntary sector support for colorectal patients it has been assumed that:

- The value of providing a one hour session of support was £10. This was derived from the ASHE value for residential care activities (£7.89), which has been adjusted for equivalent employer costs such as national insurance and holiday/medical leave.
- Each session of voluntary care lasts for one hour;
- Patients on the old care pathway and whose follow up care remains secondary care led attend 0.5 voluntary sector appointments per year (on average). Patients on the new primary care led pathways attend three voluntary sector appointments per year (on average); and
- Patients have to travel to and from the voluntary organisation premises, which (for the purposes of a simplifying assumption) was taken to be the same as travel time for a hospital appointment.
Hospital transport

The unit cost of hospital transportation has been taken from information from the Personal Social Services Research Unit (2006) Unit Costs of Health and Social Care. A unit cost for hospital transportation has not been included in the subsequent issues of Unit Cost of Health and Social Care, therefore the figure from 2006 has been converted into 2014 values using GDP deflators.

Patients and carers

The information for patients and carers was drawn from a wide range of sources, and the assumptions made to arrive at the values used are that:

- The average duration of a patient's travel time to their GP surgery or a hospital was an average drive time (in a car) value for the Sheffield Local Authority area;
- The average time a patient spends waiting for their outpatient appointment in hospital waiting rooms was assumed to be one hour. This was based on information from NHS Choices, which recommends that patients arrive 15 minutes prior to their scheduled appointment time and that hospitals target seeing patients within 30 minutes of their scheduled appointment time. Information from the NHS inpatient survey (2011-12) shows that patients at the Sheffield Teaching Hospital was not in the top 20th percentile for patient satisfaction with their waiting time and NHS choices information that patients should allow two hours for their outpatient appointment have also influenced this assumption;
- The duration of an outpatient appointment was assumed to be 30 minutes in secondary care;
- The duration of a primary care appointment was 15 minutes for Level 1 patients and 30 minutes for Level 2 patients;
- The duration of a voluntary sector appointment was assumed to be one hour;
- The average length of time patients spend waiting for a GP appointment in GP surgery (12 minutes) was based on information from the 2014 GP patient survey for the South Yorkshire and Bassetlaw Area Team; and
- The value of time taken from the Arup and Institute for Transport Studies (2014) research was from "All modes" of other transport table, and has been converted from 2008 to 2014 values using GDP deflators (£10/hour).

Employers

The assumptions made to arrive at the values used for employers are that:

- The average commute time was the average time for Yorkshire and Humberside (26 minutes);
- The employment rate for carers was taken as the average employment rate in Sheffield from the Annual Population Survey (60%);
- The employment rate for patients was estimated to be the same as the employment rate for people aged over 65 in Sheffield (8%) due to the majority of patients being aged over 65; and
- The output per employee (in Gross Value Added) was for the Sheffield area. The data source presents values up to 2012, and the 2012 figure has been inflated to a 2014 value using GDP deflators (£40,300 per year).

5.2 Calculations

The calculations used to estimate the total cost of the care pathways are described below. In making these calculations:
The costs to secondary care have been calculated by multiplying the number of patients on each care pathway by the appropriate monetary value. The costs for primary care, hospital transport, the telephone service and the voluntary sector are calculated in the same way.

The number of carers has been calculated using a ratio of the number of carers for cancer patients to the total number of cancer patients in the UK. There are an estimated 1.1 million carers for cancer patients in the UK\(^4^4\), which is around 40% of the total number of cancer patients. A conservative estimate of the ratio of carers for colorectal cancer patients to colorectal cancer patients in the target group of 30% has been used, to avoid overestimating the impact.

The estimated costs to individuals was estimated for patients who are not employed, but have to spend their free time travelling to and from, waiting for and having medical appointments when they could be taking part in other activities. This has been calculated by multiplying the number of patients who are not employed by the total duration spent on their medical appointment. This was then multiplied by the value of a person's time to estimate a monetary value for the time spent on medical appointments. The estimated cost to carers was calculated in the same way.

The cost to employers was calculated for employed patients and carers who have to spend time travelling to and from, waiting for and having medical appointments when they would otherwise be in work. This has been calculated by multiplying the number of employed patients and carers by the total duration of time they spend on medical appointments. This was then multiplied by an average hourly productivity value to estimate the monetary value.

All monetary values for years two, three, four and five have been discounted to present monetary values using discount rates.

5.3 Results of the analysis

The results from the cost comparison exercise are presented below (Table 5.1 to Table 5.3). The main points of note are that:

- **Overall, the change in pathway appears cost-neutral.** The total cost over five years of the old and new pathways is estimated at around £454,000.

- **There are differences in the ways that costs are distributed between the different stakeholders included in the analysis.** Under the old care pathway, the total cost to the healthcare sector was estimated to be just under £340,000, with estimated costs to individual patients, carers and employers in the area of over £110,000. The new care pathway has estimated costs to the health service of £330,000, representing an estimated reduction in cost of nearly £10,000, however there has also been a shift in healthcare costs from secondary care to primary care (an increase in costs in primary care of over £7,000 offsetting the larger decrease in secondary care spending). Costs to patients, carers and employers were higher under the new care pathways, estimated at over £120,000. This was primarily due to patients on the new care pathways attending the health and well-being event and additional voluntary sector appointments.

- **There are also differences in the distribution of costs over time.** When examining the results on year by year basis, the new care pathway was estimated to be more expensive in the first year of the programme. This was because of the introduction of the health and well-being event. In the second year, the old and new care pathways provide the exact same services for patients; therefore the costs are the same. However from the third year onwards the healthcare costs are estimated to be less on the new care pathways.

\(^{44}\) Macmillan Cancer Support, 2011, Understanding the UK's carers of people with cancer. The average proportion of patients with a carer is estimated to be 40%. However, around one quarter of carers support someone with breast cancer, whereas 11% of carers support someone with colorectal cancer. Therefore, 30% has been chosen as a conservative measure.
pathway, as patients are required to attend hospital less frequently. The costs to patients, carers and employers are estimated to be lower for appointments with the GP or GP nurse compared to secondary care led appointments. However, the overall costs to patients, carers and employers are higher on the new care pathway as patients access more voluntary services.

### Table 5.2 Cost of the old care pathway

<table>
<thead>
<tr>
<th>Year</th>
<th>Cost to secondary care</th>
<th>Cost to primary care</th>
<th>Cost to voluntary sector</th>
<th>Cost to hospital transport</th>
<th>Cost to individual</th>
<th>Cost to carers</th>
<th>Cost to employers</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>£95,600</td>
<td>£0</td>
<td>£1,000</td>
<td>£35,100</td>
<td>£20,300</td>
<td>£7,200</td>
<td>£17,500</td>
<td>£172,200</td>
</tr>
<tr>
<td>2</td>
<td>£53,500</td>
<td>£0</td>
<td>£1,000</td>
<td>£22,600</td>
<td>£13,500</td>
<td>£1,800</td>
<td>£11,600</td>
<td>£104,000</td>
</tr>
<tr>
<td>3</td>
<td>£41,900</td>
<td>£0</td>
<td>£900</td>
<td>£16,400</td>
<td>£10,000</td>
<td>£1,300</td>
<td>£8,700</td>
<td>£79,200</td>
</tr>
<tr>
<td>4</td>
<td>£25,000</td>
<td>£0</td>
<td>£900</td>
<td>£10,600</td>
<td>£6,800</td>
<td>£900</td>
<td>£5,900</td>
<td>£50,000</td>
</tr>
<tr>
<td>5</td>
<td>£24,100</td>
<td>£0</td>
<td>£900</td>
<td>£10,200</td>
<td>£6,600</td>
<td>£900</td>
<td>£5,700</td>
<td>£48,300</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>£453,700</td>
</tr>
</tbody>
</table>

### Table 5.3 Cost of the new pathway

<table>
<thead>
<tr>
<th>Year</th>
<th>Cost to secondary care</th>
<th>Cost to primary care</th>
<th>Cost to voluntary sector</th>
<th>Cost to hospital transport</th>
<th>Cost to individual</th>
<th>Cost to carers</th>
<th>Cost to employers</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>£100,200</td>
<td>£0</td>
<td>£1,000</td>
<td>£37,200</td>
<td>£23,700</td>
<td>£3,100</td>
<td>£20,500</td>
<td>£185,800</td>
</tr>
<tr>
<td>2</td>
<td>£53,500</td>
<td>£0</td>
<td>£1,000</td>
<td>£22,600</td>
<td>£13,500</td>
<td>£1,800</td>
<td>£11,600</td>
<td>£104,000</td>
</tr>
<tr>
<td>3</td>
<td>£40,300</td>
<td>£0</td>
<td>£1,200</td>
<td>£15,700</td>
<td>£10,100</td>
<td>£1,300</td>
<td>£8,800</td>
<td>£78,200</td>
</tr>
<tr>
<td>4</td>
<td>£16,100</td>
<td>£0</td>
<td>£2,500</td>
<td>£6,800</td>
<td>£7,200</td>
<td>£1,000</td>
<td>£6,800</td>
<td>£44,600</td>
</tr>
<tr>
<td>5</td>
<td>£15,600</td>
<td>£0</td>
<td>£2,400</td>
<td>£6,600</td>
<td>£7,000</td>
<td>£900</td>
<td>£6,600</td>
<td>£41,500</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>£454,000</td>
</tr>
</tbody>
</table>

### Table 5.4 Difference in cost between the old and new care pathways

<table>
<thead>
<tr>
<th>Year</th>
<th>Cost to secondary care</th>
<th>Cost to primary care</th>
<th>Cost to voluntary sector</th>
<th>Cost to hospital transport</th>
<th>Cost to individual</th>
<th>Cost to carers</th>
<th>Cost to employers</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>(£4,600)</td>
<td>£0</td>
<td>(£300)</td>
<td>(£2,100)</td>
<td>(£3,400)</td>
<td>(£400)</td>
<td>(£3,100)</td>
<td>(£13,600)</td>
</tr>
<tr>
<td>2</td>
<td>£0</td>
<td>£0</td>
<td>£300</td>
<td>£0</td>
<td>(£100)</td>
<td>(£100)</td>
<td>(£200)</td>
<td>(£300)</td>
</tr>
<tr>
<td>3</td>
<td>£1,600</td>
<td>£0</td>
<td>£1,600</td>
<td>£700</td>
<td>(£400)</td>
<td>(£100)</td>
<td>(£900)</td>
<td>(£4,900)</td>
</tr>
<tr>
<td>4</td>
<td>£8,800</td>
<td>(£800)</td>
<td>(£1,600)</td>
<td>£3,700</td>
<td>(£400)</td>
<td>(£100)</td>
<td>(£900)</td>
<td>(£4,900)</td>
</tr>
<tr>
<td>5</td>
<td>£8,500</td>
<td>(£2,400)</td>
<td>(£1,600)</td>
<td>£3,600</td>
<td>(£400)</td>
<td>(£100)</td>
<td>(£900)</td>
<td>(£4,900)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(£300)</td>
</tr>
</tbody>
</table>

**Figures in black represent a decrease in cost when moving from the old care pathway to the new care pathway. Figures in red represent an increase in costs.**
5.3.1 Sensitivity analysis

As noted in section 5.1.4, the results above rest upon a series of assumptions. It is therefore instructive to vary some of these assumptions to examine the impact on results obtained – a ‘sensitivity analysis’.

This section presents the findings from the sensitivity analysis. Assumptions used have been varied to provide a range of values for results. The assumptions which have been altered for this assessment are the assumptions which provide the highest degree of uncertainty. Assumptions altered, and the new assumptions used, are presented in Table 5.4.

Table 5.5 Assumptions altered for sensitivity analysis

<table>
<thead>
<tr>
<th>Assumption varied</th>
<th>Best estimate</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of referrals to voluntary sector for patients on new care pathway</td>
<td>3 for patients receiving follow up care in primary care</td>
<td>2 for patients receiving follow up care in primary care</td>
<td>4 for patients receiving follow up care in primary care</td>
</tr>
<tr>
<td>Duration of voluntary sector appointment</td>
<td>1 hour</td>
<td>30 minutes</td>
<td>2 hours</td>
</tr>
<tr>
<td>Average travel time to hospital</td>
<td>8 minutes</td>
<td>8 minutes</td>
<td>26 minutes</td>
</tr>
<tr>
<td>Average travel time to GP surgery</td>
<td>5 minutes</td>
<td>5 minutes</td>
<td>8 minutes</td>
</tr>
<tr>
<td>Average time patients spend waiting for outpatient appointment in hospital</td>
<td>1 hour</td>
<td>0.5 hours</td>
<td>1.5 hours</td>
</tr>
<tr>
<td>Proportion of patients who require informal carers</td>
<td>30%</td>
<td>20%</td>
<td>50%</td>
</tr>
<tr>
<td>Proportion of patients who require hospital transport</td>
<td>50%</td>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>Employment rate of colorectal cancer patients</td>
<td>8%</td>
<td>0%</td>
<td>39% 46</td>
</tr>
<tr>
<td>Employment rate of carers</td>
<td>59%</td>
<td>42% 47</td>
<td>70% 48</td>
</tr>
<tr>
<td>Duration of a Health and Wellbeing Event</td>
<td>5 hours</td>
<td>4 hours</td>
<td>6 hours</td>
</tr>
</tbody>
</table>

The results of the sensitivity analysis are presented in Table 5.5 to Table 5.7, alongside the best estimate values. The monetary values in the table represent the total discounted cost over five years for the whole cohort. This shows that the costs associated with providing the old care pathway range between £378,000 and £621,000. The cost of providing the new care pathway to the cohort was between £371,000 and £631,000, which means the overall cost difference between the two care pathways was between a saving of £7,400 and an additional cost of £9,600.

Despite the range of costs for the difference between the overall costs of the new and old care pathways, in all of the sensitivity analysis there was a saving to the health service.

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46 This is based on the assumption that approximately half of colorectal patients are aged between 50 and 65, and half are aged over 65. The employment rate is then calculated from the Annual Population Survey (APS).
47 This uses the employment rate for individuals aged 50+ from the APS.
48 This uses the employment rate for individuals aged 16-64, rather than 16+ from the APS.
(including voluntary sector provision). This varies from a saving of £8,700 using the higher cost estimate and of £11,400 using the lower cost estimate.

The increased cost to individuals, carers and employers should not necessarily be viewed negatively. The cost to these three groups decreases as a result of more patients receiving their care in a primary setting, but increases due to individuals attending more voluntary sector provision than under the old care pathway. Again, it is important to note that this analysis takes no account of the benefits derived from attending such support; moreover, given the voluntary nature of attendance, if individuals did not see a benefit in such support then they would not attend (so it would be for individual patients to decide whether the costs are worth the benefit).

Table 5.6 Sensitivity analysis of cost of old care pathway

<table>
<thead>
<tr>
<th></th>
<th>Best estimate</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost to secondary care</td>
<td>£240,000</td>
<td>£240,000</td>
<td>£240,000</td>
</tr>
<tr>
<td>Cost to primary care</td>
<td>£0</td>
<td>£0</td>
<td>£0</td>
</tr>
<tr>
<td>Cost to voluntary sector</td>
<td>£4,700</td>
<td>£1,200</td>
<td>£9,400</td>
</tr>
<tr>
<td>Cost to hospital transport</td>
<td>£94,800</td>
<td>£75,900</td>
<td>£113,800</td>
</tr>
<tr>
<td>Cost to individual</td>
<td>£57,200</td>
<td>£43,700</td>
<td>£65,100</td>
</tr>
<tr>
<td>Cost to carers</td>
<td>£7,600</td>
<td>£5,100</td>
<td>£15,800</td>
</tr>
<tr>
<td>Cost to employers</td>
<td>£49,300</td>
<td>£12,600</td>
<td>£177,000</td>
</tr>
<tr>
<td>Total Cost</td>
<td>£453,700</td>
<td>£378,400</td>
<td>£621,200</td>
</tr>
</tbody>
</table>

Table 5.7 Sensitivity analysis of cost of new care pathway

<table>
<thead>
<tr>
<th></th>
<th>Best estimate</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost to secondary care</td>
<td>£225,700</td>
<td>£225,700</td>
<td>£225,700</td>
</tr>
<tr>
<td>Cost to primary care</td>
<td>£7,300</td>
<td>£7,300</td>
<td>£7,300</td>
</tr>
<tr>
<td>Cost to voluntary sector</td>
<td>£8,200</td>
<td>£1,700</td>
<td>£15,400</td>
</tr>
<tr>
<td>Cost to hospital transport</td>
<td>£88,900</td>
<td>£71,100</td>
<td>£106,200</td>
</tr>
<tr>
<td>Cost to individual</td>
<td>£61,500</td>
<td>£46,200</td>
<td>£69,000</td>
</tr>
<tr>
<td>Cost to carers</td>
<td>£8,100</td>
<td>£5,400</td>
<td>£16,800</td>
</tr>
<tr>
<td>Cost to employers</td>
<td>£54,300</td>
<td>£13,600</td>
<td>£190,300</td>
</tr>
<tr>
<td>Total Cost</td>
<td>£454,000</td>
<td>£371,000</td>
<td>£630,700</td>
</tr>
</tbody>
</table>

Table 5.8 Difference in costs between old and new care pathways

<table>
<thead>
<tr>
<th></th>
<th>Best estimate</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost to secondary care</td>
<td>£14,400</td>
<td>£14,400</td>
<td>£14,400</td>
</tr>
<tr>
<td>Cost to primary care</td>
<td>(£7,300)</td>
<td>(£7,300)</td>
<td>(£7,300)</td>
</tr>
<tr>
<td>Cost to voluntary sector</td>
<td>(£3,500)</td>
<td>(£500)</td>
<td>(£6,000)</td>
</tr>
<tr>
<td>Cost to hospital transport</td>
<td>£5,900</td>
<td>£4,800</td>
<td>£7,600</td>
</tr>
<tr>
<td>Cost to individual</td>
<td>(£4,300)</td>
<td>(£2,600)</td>
<td>(£3,900)</td>
</tr>
<tr>
<td>Cost to carers</td>
<td>(£600)</td>
<td>(£300)</td>
<td>(£1,000)</td>
</tr>
<tr>
<td>Cost to employers</td>
<td>(£4,900)</td>
<td>(£1,000)</td>
<td>(£13,300)</td>
</tr>
</tbody>
</table>
5.4 Recommendations for further research

This can be viewed with a high level of confidence for the costs which have been covered. However, there were some potential impacts of the switch to a stratified approach to follow-up care for colorectal cancer patients from the previous one size fits all approach. It has not been possible to assess these impacts due to a lack of evidence on the impacts of the new care pathway. These include:

■ Potential improvements in health outcomes. The analysis assumes that the health outcomes remain the same under both care pathways, in terms of survival rates, quality of life and future treatment for complications or relapses. No evidence was sought on these impacts, therefore the economic impact of changes in health outcomes could not be modelled. It is recommended that research was carried out to identify changes in health outcomes in the future.

■ A potential impact of the introduction of the new care pathway was that it would promote self-management of all health conditions, and potentially reduce the number of primary care appointments colorectal patients had for conditions other than colorectal cancer. Again, given the early stage of implementation, no evidence was found to confirm or refute this. Future research into the number of primary care appointments patients use on each care pathway would identify if this potential impact was observed.

■ The volume of telephone consultations with a Clinical Nurse Specialist was expected to change. However, no evidence could be found to quantify this change. Further research into the number of telephone calls to a CNS on both care pathways could be carried out to see if this impact was observed.

Additionally, the research carried out for this report was forward looking, estimating the expected costs of old and new care pathways. Additional empirical work, done as the pathways become more embedded, would usefully refine the analysis presented here.
6 Summary of lessons from other areas

Section summary:

Work outside of Sheffield has been varied, with some projects only just beginning to look at system-wide approaches to survivorship. Most progress in this respect has taken place in Doncaster, where the project has focussed on co-production: using outcomes identified by PABC as the starting point to improving services. In Barnsley, the CN project has met with some challenges but will continue to progress with learning from current work in Sheffield and Doncaster. Work in Rotherham is still at an early stage: the 1-2-1 project has been tested in urology and will now be extended to patients in all cancer MDTs, including colorectal.

Evidence suggests that projects thus far have been implemented in relative isolation. Although there is awareness of other projects, shared learning has been limited. Indications for shared learning in the future came only from Barnsley which has benefitted from key staff moving into the area from Sheffield and Doncaster.

Section 2 described the components of the SP being implemented in each of the localities. In this section we turn to focus on progress with implementation and outcomes reported. This section draws on interview findings, augmented by project documents.

6.1 Doncaster’s co-production approach has focused on building access to, and capacity in, community services

The aim of the Doncaster project is to improve the quality of life for people in Doncaster living with and beyond cancer. Within this, the project sought to formalise care pathways so that there were stronger links between medical and social models of care.

The starting point for this work was to identify outcomes (‘I’ statements) as defined by PABC. Involvement of PABC was (and continues to be) fundamental to the project - both in terms of its design and its operation. The workstreams defined in response to the outcomes (described in section 2) have given rise to a number of new and revised services. One of the main developments in this respect is the ‘Living Well hub’, which supports better access to services which meet a range of holistic needs. This is the entry point for PABC who may either self-refer or be referred in by professionals.

The hub acts as a single point of access for between 80-90 local services. It establishes relationships with the voluntary and community sector (VCS) organisations which are running these services. When referrals are made to the hub, PABC are assessed and services are assembled around individual needs. The approach used by hub staff is based on MI. People entering the service may then be referred on to:

Emotional support
If there is a need for emotional support then PABC can be put in touch with ‘cancer buddies’ who are volunteers (themselves affected by cancer), who provide emotional support.

Social support
In the cases where social needs are identified the hub works with the CIC ‘Meeting New Horizons’, in order to provide support for the PABC. Services, largely provided by the VCS, have been through a ‘survivor friendly kite marking’ process. In order to get this mark, services have to meet certain criteria developed by PABC. The services under this scheme

49 PID: Doncaster cancer survivorship project
50 Project Mandate (2012). Improving the quality of life for Doncaster people following the diagnosis and treatment of cancer. (Cancer survivorship in Doncaster).
provide support that relates to the ‘I’ statements. The PABC is referred from the hub to the CIC, which is able to conduct home visits, and carry out a full assessment, before supporting access to relevant services through supported signposting:

“Rather than leaving a list of phone numbers and saying ‘here is a list of people who could help you’, they’re actually doing the leg work and contacting those organisations themselves and getting a named individual at a named time who addresses the issues they are concerned with”.

The CIC was already commissioned by the local authority to develop resilience amongst the VCS, and the service offered as part of this project was commissioned by Macmillan as a ‘bolt on’ to support access to services that are ‘survivor friendly’, giving them a quality mark. Macmillan support has therefore been in terms of coordinating, training and quality assuring existing services, rather than setting up new services. Fundamentally, the aim has been to promote recovery and self-management:

“We’ve tried to get away from a sort of NHS view of giving people things, to an approach where people take control of their own condition. We’re trying to engender self-management purely because ultimately there are going to be too many survivors for the NHS to hold everybody’s hand”.

The above developments are also noteworthy for not following a specific and set ‘recovery package’; instead, the approach has been to consider the functions / support required and the best means of addressing this locally.

Other developments have included:

- **Working with carers** – Links have been established with existing carer organisations in Doncaster, and the workstream lead is working with other workstream leads to ensure carer perspectives are included in all work going forward.

- **Working with employers** – Although this has not to date been a well-developed area of work, there are plans to engage with the Chamber of Commerce to raise awareness of employment issues and cancer survivorship. Working through cancer training has also been delivered to the council (executive level) and acute trusts.

- **Implementation of the recovery package** – Efforts to move secondary care follow-up for colorectal cancer into primary care are still at an early stage. So far, the HNA has been implemented in colorectal (and breast) secondary care. GP facilitators have also engaged with about 70% of GP practices; visits include education and awareness in relation to survivorship issues; TSs; and CCRs. The visits are also used as an opportunity to promote the hub. Survivorship workforce events have also been held to support culture change. Feedback for these events has been positive.

Interviewees reported that the project is progressing well, with its strengths lying in the co-production model and engagement with community services:

“We’re fairly sure, because of the process we’ve been through, that we have defined outcomes that are valued by patients, survivors and carers.”

“They have developed a really good infrastructure on the ground, with a single point hub so that people can be triaged and referred out into community services.”

The co-production approach has helped to gain support from PABC and also commissioners and wider stakeholders. This has also led to increases in volunteering which the service then benefits from in terms of ‘cancer buddies’.

Local commissioners and the local authority are also well engaged, and leadership events with clinicians and leaders – where PABC talked about their needs – have been successfully held. Facilitators for success were explained in terms of the engagement of multiple stakeholders, and also in terms of having a strong project lead who had good project management skills, but was also able to ensure “ownership on the ground”, whilst facilitating engagement from statutory stakeholders.
6.2 **Bassetlaw has worked with a VCS based survivorship team**

Work in Bassetlaw is just beginning. The model being trialled is based on links between multi-disciplinary teams (MDTs) and a survivorship team located in a local VCS organisation. Many challenges have been encountered in terms of generating wider strategic engagement and engagement with PABC. The VCS organisation is well located to broker support form a range of services, however it lacks the capacity to carry out engagement work more widely: "In terms of re-designing systems, we’re nowhere near even starting…it’s not system-wide". Geographies in Bassetlaw also present some challenges as social care and health commissioners are not co-terminus, making collaboration between the two systems more difficult.

6.3 **To date, Barnsley has focused on care navigation**

The Barnsley care navigator (CN) project aims to improve quality of life for people living with/beyond colorectal cancer through integrating health and wellbeing issues, and empowering them to maintain and improve their own health.\(^{51}\) The pilot supported by Macmillan ended in August 2014, and the CCG has now sustained it. Macmillan funding has therefore acted as ‘pump priming’ for the service. Work is continuing to look at risk stratification approaches to moving follow-up from secondary to primary care (see Section 2).

A number of challenges to implementation were described by interviewees:

- **Low referrals** – Very few patients have been recruited to the CN service because of the short timescale and size of the colorectal cohort.

- **The pace of change is slow** – It was noted that change has taken a long time to take place, with much time taken in planning of pathways (rather than taking a more iterative ‘plan-do-review’ approach).

- **Inter-organisational trust** – Trust across the system is integral to the success of survivorship pathways. One interviewee talked about the lack of trust between primary and secondary care, with consultants and nurse specialists fearing to ‘let patients go’ because of a lack of confidence in primary care. Additional capacity provided by Macmillan is helping. It was also noted that some success had been made with trust in the CN service, with the colorectal team having started off as suspicious of the service, but now advocating for it. This was facilitated by positive feedback from PABC using the service. There is however some continuing resistance where services are stretched: "They just don’t have the breathing space to implement change.”

- **Financially challenged hospitals** – The local context presents challenges to pathways which reduce activity in secondary care. The risk stratified approach presents a challenge to the hospital who do not want to lose tariff payments associated with cancer follow-up. It was noted by one interviewee that the financial system doesn’t lend itself to joined up pathways between primary and secondary care.

Despite the challenges highlighted above, interviewees reported that in general the project has worked well, and a number of positive outcomes were noted:

- **Spread** – The CN service is now beginning to be rolled out to other tumour sites, with champions in the hospital trying to introduce it to their specialist nursing colleagues in other areas. This is paving the way for other LTCs too, and respiratory care is being considered as another area of development for the service;

- **Patient feedback has been positive** – Although the numbers of colorectal patients accessing the service has been low, and it is difficult to attribute cause and effect (there

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\(^{51}\) Macmillan case of need: Barnsley colorectal survivorship care navigation pilot.
are other parallel initiatives e.g. an exercise programme), there are data suggesting improvements in patient satisfaction and self-management;

- **Communication has improved** – Although communication has improved between different sectors of health, this now needs to be extended into the VCS.

**Learning from other areas will be used in work going forward**

The project will benefit from learning in Doncaster and Sheffield due to the movement of key staff across the two areas. In particular the Doncaster project lead and the Sheffield project lead have moved into Barnsley. These were described as valuable assets in terms of spreading the message of the survivorship ethos. In addition, the programme lead was described as important in ensuring that lessons across projects are shared:

“So let’s take the learning and all the best bits from these projects [in Sheffield and Doncaster] and make sure that it’s absolutely captured and applied in Barnsley”.

6.4 **Rotherham has trialled a 1-2-1 model in urology**

The 1-2-1 project in Rotherham aims to improve care and support coordination, and deliver improved health and wellbeing outcomes for those living with/beyond cancer in the community setting52. The project was implemented with urology patients, and there are further plans to extend this to all cancer MDTs.

The project began taking cases in June/July 2014, and at the time of interviewing there were around 60 active clients, with an average of three new referrals a week coming in. Interviewees notes that the referral rate was challenging; this was explained by the difficulty in establishing new ways of working with clinicians and senior nurses, who may not yet be fully convinced of the benefits of the service. Other challenges noted were gaining consistent support from the CCG, and engagement with the primary care sector. In particular, the project has struggled with recruiting peer GPs who want to take on an educational role to support colleagues in primary care.

Interviewees also noted elements of the project which had worked well:

- The profiling work added value to the project in the way it allowed for a systematic breakdown of what patients need (based on professionals’ views), with inputs from different parts of the pathway.

- Support from Macmillan has been invaluable both in terms of funding, but also in terms of access to training, which included cancer care course for nurses, MI, and service improvement courses. In addition Macmillan’s role in providing key literature and facilitating communication across organisations has been useful.

- Good appointments to the liaison nurse and cancer support worker role have been made.

The project has not yet been evaluated (plans are in place for this to take place in 2015), but letters have been received from PABC who have indicated their satisfaction with the service. Future evaluation plans will consider using the ‘friends and family test’ and looking at data on response times.

The project is due to end in May 2015, but extensions of the posts are being considered.

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52 Macmillan case of need: Rotherham Primary Care-led Adult Cancer Survivorship pilot.
7 Lessons from across the programme

Section summary:

The next phase of the SP is being developed. This presents an opportunity to review experiences from this phase: to ask what can be learnt in promoting system change and, therefore, what should the next programme ‘look like’? The evidence presented here recommends a more tightly focused programme, with a clear theme and agenda that can be implemented locally and learnt from. It also suggests that a longer timeframe and new set of skills is needed. Finally, it is clear that Macmillan has added significant value and should continue in its efforts to redesign the system.

The design and evolution of the SP has been a key theme in the evaluation. The SP was assembled from a series of loosely-connected local survivorship projects, rather than it being designed as a single programme with shared aims, objectives, activities, and desired outcomes. Defining ‘the programme’ has been a challenge for the evaluation.

These issues come to the fore when thinking about the next phase of the SP. There is a fundamental question as to whether the SP should proceed ‘as a programme’ – or operate solely at the local level. Should the SP develop as a programme, there are then choices to be made about its focus, design and structure.

This evaluation has a role to play in informing these decisions. Evidence gathered from this phase of the work can be used to learn lessons and improve future efforts. Moreover, as well as informing the next phase of the SP, some of the findings from this phase are likely to be of interest to Macmillan in its efforts to ‘re-design the system’.

This section addresses these topics. It draws upon the stakeholder interviews and the reflections of the evaluation team.

7.1 There is a need for a clearer ‘programme theme’

The SP was not a programme in the traditional sense. Instead, it came together over time and comprised a series of local projects and initiatives. As one interviewee noted: “What we have here is a collection of projects that came together as a programme, so they didn’t necessarily have coherence, it was an emergent programme.”

This presented challenges in terms of management, governance and oversight. While not necessarily detrimental to the delivery of the work, it has been challenging for the programme team to maintain oversight of activity of the different areas. More substantively though, the programme (as a programme) has not been reporting into decision making structures; opportunities for influence may therefore have been lost.

The breadth of local diversity has also made it difficult to frame and communicate the programme. Within the interviews, there was some divergence of view as to whether (for example) the aim of the programme was to: arrive at a commissionable / coherent package of care for CCGs to take forward; and/or to ‘simply’ re-shape existing services; and/or to stimulate the development of other ‘non health’ services; and/or engage local authority commissioners; etc.

These points are not listed to suggest incoherence or fundamental disagreement, but to show how the same programme has been viewed in legitimately different ways – making the task of internal learning and external communications more difficult. It should also be noted that these challenges were present despite having an agreed set of aims and objectives in a terms of references.

One response to this would be to ‘go local’ – to recognise that change is implemented locally and to remove (from this perspective) supervening programme structures. Yet no stakeholders interviewed advocated this response. Moreover, going local would miss opportunities for learning given the shared problem faced and broad set of solutions
proposed. It would also forego some of the value generated by emerging practice within the SP – for example, that work in Barnsley will be informed by learning from Sheffield and Doncaster.

Instead, the best way forward seems to be to retain local activities within an overall programme approach – but to begin with a tighter definition of what the programme is there to do. 'Survivorship' has been too broad a frame; for there to be a practical / applied sense of shared learning (at strategic and operational levels), then there needs to be a clearer sense of what each area is working towards.

Accepting the limitations of the evaluation team’s knowledge – and the fact that actors within the SP, Macmillan and local system will know of other relevant initiatives - the Macmillan / NHS England ‘Living With and Beyond Cancer Programme’ (following the NCSI) seems to provide a useful framework. It has specific components that the programme can promote and that localities could select and work towards implementing. Moreover, within the Living With and Beyond Cancer Programme there is an explicit aim of influencing NHS (and presumably other) services. (It is less clearly focused, but the system map at Figure 2.2 also provides a means of showing different possible areas for intervention).

Programme structures should follow this purpose. We return to this in the final section of the report, but for now we note that taking an overall programme level framework, which is implemented with different emphases in different local areas, lends itself to a clear focus on practical learning and (following from this) wider strategic influence.

7.2 Programmes of system change take far longer than ‘traditional’ programmes; they also require different skills and perspectives

The next clear lesson from the SP is about the time taken to implement system change. This was a strong theme in the stakeholder interviews, for example: “For the first six months at least, it was a lot of knocking on doors, meeting people, going out into primary care to just even raise awareness of survivorship”. The main implications were cited as being two-fold, in that a short time frame:

- Makes implementation more difficult and the SP has not achieved all that was planned (“…we’ve only just started, it’s the tip of the iceberg…”); and
- Creates doubts about sustainability once the programme has ended (“…[I don’t know if changes are] embedded enough such that when we take out the dedicated resource and support that it won’t just go back to ‘business as usual.’”)

The implication therefore is that programmes of system change need a longer timeframe. Again, we return to this in the final section of the report; here we note that the requirement for a longer timeframe is largely a function of the mechanisms for change when approaching systems. This is because, alongside the additional resources provided by Macmillan, the main mechanism for change within the SP seems to have been engaging stakeholders.

This engagement has taken place across the system (primary-secondary; commissioning-provision; clinical-managerial; health and non-health) and at all levels (senior strategic-middle management-frontline). They have been engaged using different approaches and tools, all united by some degree of common narrative relating to: the changing nature of cancer and increased incidence of survivorship; resource constraints and consequent need to change models of care; and therefore the merits of adopting approaches advocated under the SP.

This takes time. It hinges upon creating / sustaining effective relationships and changing mindsets. As interviewees noted:

“Professionals won’t let go of patients until they see that there’s something [a service] they can trust – and it’s not something they can trust, it’s someone they can trust to let their patient go to. Referrals only start increasing after we’ve done face-to-face engagement events.”
“You’re dealing with people, not just organisations. We were dealing with one person at [mentions trust] and it wasn’t really happening. Then [mentions another person] started and we’re away”.

“[it takes time for]...clinicians to let go. Getting feedback that having let go is actually benefiting patient more. And that it’s not just about the patient, but also their carers and families. So there’s a big shift there: from ‘doing to’ the patient to ‘doing for’ people affected by cancer”.

Moreover, the challenges of using such ‘soft’ mechanisms (relative to, say, regulation or performance management) in a system that is already under considerable pressure was also noted:

“They’re [the NHS] being squeezed tighter than ever because of all the savings that have to be made, they have increased workload... and there’s no capacity to implement this huge cultural change, it needs dedicated time.”

“People buy into the principle, but are turned off the reality if they don’t get the resource coming with it”.

Finally, and building upon these points, this requires a set of skills and tools over and above those of traditional programme management. It requires an ability to ‘see’ systems (e.g. realising that changing ‘x’ in secondary care may require changes ‘y’ and ‘z’ in primary care, which in turn requires ‘a’ and ‘b’ in the voluntary sector), and to exercise change management skills based around the use of (for example) narrative and persuasion, rather than more standard approaches of giving / withholding resources.

Vital tools available to Macmillan, as a patient charity, include the power of its brand and its ability to articulate the user voice. The power of this has been seen in Doncaster, where having a set of user-defined outcomes has helped to engage and persuade stakeholders, advancing the survivorship agenda using the patient’s perspective. As one interviewee noted:

“I'm completely bought in to the role of facilitator, influencer, and broker. I think our [Macmillan’s] existing relationships and public brand have been key to our legitimacy in doing that...the complexity of these changes, which are not just service improvements, but are about cultural change, requires the organisation to switch mindset from being a two to three year instigator of programmes to a ten year facilitator.”

7.2.1 A sequenced combination of ‘push’ and ‘pull’ is needed to enact change

As noted above, system change requires a system perspective. It is not enough to improve services in one part of the system if effective provision requires changes across institutional and sectoral boundaries.

There is rich learning from the SP in this respect. In particular, the very different approaches taken in Sheffield and Doncaster show that, while there are legitimately different routes to the same ends, there is a need to sequence change such that patients can be ‘moved’ from provision in one part of the system to provision in another.

The framework of ‘push and pull’, noted by two interviewees, is useful in describing the changes made in each area:

■ In Sheffield, the programme started in secondary care, building out into primary care and then wider services – helping services to reduce unnecessary use of secondary care. This approach can then be categorised as ‘pushing out’.

■ In Doncaster, the programme started in community / voluntary services and is building into primary and secondary care. This can be thought of as ‘pulling in’.

While ostensibly very different – Doncaster has made use of community development approaches; Sheffield has acted on systems of care – there is no fundamental conflict and both are likely to be needed to enact the system-wide changes desired. This also further underscores the above point about the need for new skills in redesigning the system.
7.3 Macmillan has provided clear strategic added value through the SP

The concept of 'strategic added value' (SAV) is sometimes used by evaluators as a means of accounting for the less tangible impacts that interventions have. This is over and above the effects of direct support / service provision and typically includes things such as persuading others to act in a way that promotes a particular agenda. SAV has been defined in various ways; here we have defined it as:

- **Leading** – has the SP acted to (co)define and advance an agenda, raising its profile?
- **Catalysing** – has the SP acted to stimulate action on the agenda developed?
- **Coordinating** – has the SP reduced duplication and enhanced learning by bringing actions together into a common framework?

Primarily, the question of SAV within the SP is a question of the added value of Macmillan’s involvement. This was therefore explored during the stakeholder interviews.

The main finding here is that Macmillan has added value to the system across the three elements listed above. Macmillan has:

- Helped to **define the survivorship agenda** through national and local work (e.g. through co-production work in Doncaster; using NCSI as a framework; using RfD to examine risk stratification; using research into likely future trends in survivorship):
  
  "I think we’ve [Macmillan] been influential in pushing survivorship."

  "Macmillan bring fresh eyes onto our world. The area managers are inherently part of the programme team. We constantly challenge one another in terms of direction of the programme."

- **Stimulated action** – both by bringing additional resources and programme disciplines:
  
  "Without Macmillan’s support and resources it [the project] wouldn’t have been as good as it is – and it’s getting national attention”.

  “Macmillan have driven this, I would like them to continue to develop this, and this should involve replacing [mentions postholder’s name] role in the community and supporting the specialist cancer services.”

- **Convened and coordinated** the system – e.g. through conferences and events, joint training sessions, programme structures and stakeholder engagement:
  
  “Macmillan work at every level, from HQ all the way down, they’re in everywhere. That makes a difference because they drive forward policy and support things. Their integration into strategy, delivery and implementation is absolutely crucial.”

This provides both confirmation of the strategic choice to ‘redesign the system’, and a basis from which to proceed in thinking about the next phase of the SP.

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53 It was a central feature of evaluations of Regional Development Agencies (RDAs), since a significant element of RDA activity was (e.g.) stakeholder engagement, strategy development, research, R&D investment, seedcorn funding etc. This activity was seen as having a value – albeit an intangible one – over and above that of the more mainstream / programmatic investments made by the RDAs. SAV was therefore developed as a framework for capturing this.
8 Conclusions and recommendations

Phase 2 of the SP was launched in the Autumn of 2013, and will be coming to an end by April 2015. Information presented in this report has covered implementation of this phase, and early outcomes where possible. A large amount of ground has been covered in the programme thus far in terms of raising the profile of survivorship locally and building relationships across sectors and organisations. Going forward, it will be important to ensure that learning generated by the SP is used to further embed changes made thus far.

It is with this in mind that we draw the following main conclusions:

The rationale for the SP continues to be strong

The programme has been implemented in a challenging context, which will continue to be relevant for the foreseeable future. The demands of an ageing population and a financially stretched public sector are now well rehearsed. Coupled with medical advances, this means an increased number of patients living for longer with/surviving cancer. This requires a change in how patients are supported: there needs to be a shift in care, where patients are supported holistically beyond diagnosis and treatment.

The SP sets out to meet this need. It has taken significant steps towards providing more holistic care and support. Macmillan’s role in this has been vital. They have: led the survivorship agenda across the region; advocated for the patient voice; made significant contributions towards bringing different parts of the system together; and been instrumental in promoting (and funding) the required changes.

The SP was not strategically designed

The programme has been implemented against a challenging backdrop: structural changes in the NHS and the disbanding of the cancer network has presented difficulties for continuity in terms of leadership and governance. Our findings have shown that the SP evolved from a set of discrete projects across the localities. These projects are connected by a broad focus on survivorship, and have been implemented at different stages of the programme. Although efforts have been made to share learning, the aims, objectives, activities, and desired outcomes are not consistent across the SP.

Risk stratification seems appropriate but takes time

Work in Sheffield suggests broad support for the use of risk stratified pathways. The programme also shows that implementing these pathways is very difficult in practice. In particular, clinicians in secondary care need to have confidence in, and advocate for change in accordance with revised pathways. Primary care stakeholders also need to be engaged from the start — i.e. through involvement in planning what the revisions will be, before championing these amongst their colleagues in practice.

Ongoing engagement of primary care is vital for risk stratified survivorship pathways to become embedded across the system. Significant efforts were made in Sheffield to engage primary care, through the LCS; learning and development activities; dedicated support from the 1-2-1 project; and CCG resources. This meant that implementation took longer than expected. The longer lead-in time required for implementing change also had an impact on the evaluation. Methods had to be revised to align with programme delivery, and the ability to report on impact is limited since patients discharged into primary care follow-up are still at an early stage in these parts of the pathways.

Building in more holistic care requires engagement across the system

Where Sheffield work has focussed on ‘pushing’ patients from secondary into primary care, work in Doncaster has focussed on ‘pulling’ patients out of care and into community-based support. Work in Doncaster has therefore generated important learning around how to engage the VCS and PABC more broadly. Experience from Doncaster shows that adopting a co-production approach, where PABC are placed at the forefront of change, is a powerful tool for generating engagement across the system. It has also shown the value of working to
adapt existing community services and resources to meet the needs of people living with and beyond cancer.

The SP has therefore shown that the focus need not be on providing new services (except where thorough needs assessments show significant gaps), but that it is important to coordinate existing services. Workforce development has been an important mechanism here: both in terms of formal training and learning, and in terms of the cultural changes / gains in understanding from bringing different people together ‘from across the system’.

The SP has provided lessons as to how emotional and psychological support is utilised by PABC. Formalised / programmatic support is not always required even when PABC are going through emotionally demanding times. Informal support networks are greatly valued, as is flexible community based provision. Informal emotional support provided by secondary care nurses is also valued. PABC do feel reassured however by knowing how to access more formalised support should they require it.

There are early indications that the revised pathways in Sheffield are acceptable

Although at a very early stage, our findings suggest that the revised pathways are accepted (at least in theory) by stakeholders in secondary and primary care. Peer research shows that PABC also accept the revised pathways as long as they are given information about them from an early stage. There is however some apprehension about leaving secondary care follow-up amongst some PABC, partly due to the excellent care that they say they have received in secondary care.

Accepting its limited nature, the economic analysis undertaken also supports revisions made to the pathways. Results suggest that costs of the pathways are broadly neutral. The new arrangements should then be preferred if patients can be shown to have benefitted, or (assuming similar benefits to them), the system has become more sustainable as a result. The results are also likely to be useful in that they cover the entirely of the pathway – including support provided by the VCS – providing a broader view for commissioners considering costs associated with changes to the system.

Based on these conclusions we make the following recommendations:

Macmillan should continue to promote survivorship in the area

Significant progress has been made in terms of implementing changed ways of working. The potential for improving outcomes for PABC – particularly in terms of more positive experiences and empowerment to ‘move on’ – is great. Macmillan is highly regarded for their role in the SP, and are well placed to continue to drive this work forward. They should therefore continue to promote this agenda, convening and influencing different parts of the system and supporting localities to implement learning from other areas into their own plans.

Project work in localities needs realigning to shared aims

Macmillan and partners are currently working with a commissioning support organisation to re-shape the SP for ‘Phase 3’. This evaluation suggests that for the next phase more attention should be given to its operation as a cohesive programme. Whilst allowing local flexibility is important, there is much to gain from working towards shared aims which are more tightly defined. We recommend that more formal mechanisms for sharing learning are established before shared plans are developed across the localities, (e.g. through quarterly or bi-monthly meetings attended by area leads and expert speakers; visits to other areas; implementation support workshops). Governance functions should be separated from this ‘learning’ function, and be kept local as far as possible.

Aligning activities to the Living With and Beyond Cancer Programme / NCSI seems a sensible approach to achieving coherence. Thus far projects in different areas outside of Sheffield have started to look at some components of the recovery package. It would therefore be a natural progression to move this work on by looking at all four components
(i.e. the HNA; TS; HW day; and the CCR) – or at least the function they perform. For Sheffield this would mean addressing where it is feasible to move closer to the national model – e.g. through earlier risk stratification. For Doncaster, this might mean showing how the intention of the recovery package can be met via different means.

**Engagement across the system should be planned into timescales**

One of the key lessons from the SP has been that relationships across the system take time to develop. Implementing system change is an ambitious task. It is therefore important to build engagement work into programme delivery plans from the outset. This is an integral component of programme delivery, and the time required to do this should not be underestimated.

The same is true of workforce development. Again, this should be thought of in terms of formal training opportunities and ‘bringing people together’ to better understand the way that systems of care need to change to better meet the needs of people living with and beyond cancer. Macmillan has a vital role to play in this respect: it has an established learning and development offer, alongside significant ‘convening power’ and the ability to bring different elements of the system together.

The investment of time required in order to implement change across a system requires long term commitment from programme developers. For the SP to realise its full potential changes made need to become properly embedded so that they become ‘business as usual’. We recommend that this would require an investment of somewhere in the region of five to ten years, rather than the usual three to five.

**Strong support for patients is required at discharge**

Our findings have illustrated how patients should continue to be prepared for earlier discharge in early stages of the pathways. Moreover, the apprehension that some patients feel upon secondary care discharge shows the need for a strong handover at this point. This needs to be followed through in primary care at the point of discharge to them. Primary care duties thus far have focused on CEA blood monitoring and the CCR. There is scope for considering the inclusion of communication to patients once they are handed over to their care. Patients would benefit from a system which is consistent with secondary care – where for example a letter is sent to them or a visit is arranged to acknowledge that they are now under primary care follow-up. There is also a role for primary care HCPs to offer more (informal) emotional support, given that the loss of this upon discharge is acutely felt by some patients.

**Holistic support should continue to be addressed iteratively**

Our findings suggest that support for non-medical needs requires flexibility. PABC have indicated that different individuals prefer different support mechanisms, whether this be in the form of the HW day, a structured support course such as CALM, or a support group.

The iterative approach adopted thus far should continue into the next phase. There has been value in trialling different modifications to interventions, and if need be deciding that they should be withdrawn (e.g. CALM) or expanded on (e.g. HW day).

**Further research and evaluation is needed to capture impact**

Findings thus far have indicated that drawing any firm conclusions on impact of the SP would be premature at this stage. In particular the programme is still at an early stage in terms of realising impacts for PABC. As the SP moves into the next phase, it is important to develop robust mechanisms for monitoring and evaluation, and then to use the data generated from this to track short, medium, and longer term outcomes. It has been too early for example to comment on outcomes of earlier discharge in relation to morbidity, mortality, and detection of recurrences.

Our economic analysis was also limited to a cost comparison exercise due to the early stage of the project. Further research is needed to assess how costs change as the pathways become further embedded. This should be done with commissioning in mind; changes to the
system of the type enacted under the SP imply shifts in cost (e.g. increasing the role played by the VCS). These shifts can be made sustainable through changes in commissioning.
## Annex 1  Stakeholders interviewed

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<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Role</th>
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<tbody>
<tr>
<td>Shwan Amin</td>
<td>Sheffield Teaching Hospitals</td>
<td>General and colorectal surgeon</td>
</tr>
<tr>
<td>Jill Badger</td>
<td>Hardwick CCG</td>
<td>Commissioner</td>
</tr>
<tr>
<td>Penny Brookes</td>
<td>Sheffield Teaching Hospitals</td>
<td>Patient Representative/Executive</td>
</tr>
<tr>
<td>Sandra Clarkson</td>
<td>Macmillan</td>
<td>Macmillan Development Manager</td>
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<tr>
<td>Will Cleary-Gray</td>
<td>NHS Sheffield</td>
<td>Programme Director, CCG Collaborative Working Together Partnership</td>
</tr>
<tr>
<td>Liz Cooper</td>
<td>Sheffield Teaching Hospitals</td>
<td>Colorectal Matron Practitioner</td>
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<tr>
<td>Joanne Dixey</td>
<td>Sheffield Teaching Hospitals</td>
<td>Clinical Specialist Physiotherapist</td>
</tr>
<tr>
<td>Rosalind Eve</td>
<td>Sheffield Age UK</td>
<td>Chief Executive Officer</td>
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<tr>
<td>Louise Foster</td>
<td>Sheffield Teaching Hospitals</td>
<td>Colorectal Nurse Practitioner</td>
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<tr>
<td>Jackie Gladden</td>
<td>NHS Sheffield</td>
<td>Senior Commissioning Manager</td>
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<tr>
<td>Dr Amin Goodarzi,</td>
<td>Dykes Hall Surgery</td>
<td>GP</td>
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<tr>
<td>Dr Anthony Gore</td>
<td>NHS Sheffield</td>
<td>GP Cancer Lead</td>
</tr>
<tr>
<td>Diana Greenfield</td>
<td>Sheffield Teaching Hospitals</td>
<td>Nurse Consultant</td>
</tr>
<tr>
<td>Marianna Hargreaves</td>
<td>NHS Sheffield</td>
<td>Commissioner</td>
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<tr>
<td>Margaret Harrison</td>
<td>Macmillan</td>
<td>Macmillan Learning &amp; Development</td>
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<tr>
<td>Cat Hayden</td>
<td>Macmillan</td>
<td>Senior Occupation Therapist</td>
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<tr>
<td>Karen Holmes</td>
<td>Weston Park Cancer Information and Support Centre</td>
<td>Centre Manager</td>
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<tr>
<td>Sue Hughes</td>
<td>NHS Sheffield</td>
<td>Practice Nurse</td>
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<tr>
<td>Dawn Lockley</td>
<td>Sheffield City Council</td>
<td>Physical Activity in Cancer Representative</td>
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<tr>
<td>Tom Noel</td>
<td>Macmillan</td>
<td>Macmillan Development Manager</td>
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<tr>
<td>Sam Maher</td>
<td>Sheffield Teaching Hospitals</td>
<td>Surgical Service Manager</td>
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<tr>
<td>Heather Marrison</td>
<td>Sheffield Teaching Hospitals</td>
<td>Colorectal Nurse Practitioner</td>
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<tr>
<td>Louise Metcalfe</td>
<td>NHS Sheffield</td>
<td>Cancer Survivorship Project Nurse</td>
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<tr>
<td>Richard Metcalfe</td>
<td>Doncaster / Bassetlaw CCG</td>
<td>Commissioner</td>
</tr>
<tr>
<td>Verna Morris</td>
<td>Sheffield Hallam University</td>
<td>Motivational Interviewing Trainer</td>
</tr>
<tr>
<td>Liz Newell</td>
<td>NHS Sheffield</td>
<td>Complex Case Manager</td>
</tr>
<tr>
<td>Jane Parker</td>
<td>South West Yorkshire Partnership Foundation Trust</td>
<td>Lead Colorectal/stoma care CNS</td>
</tr>
<tr>
<td>Vicky Reverelle</td>
<td>Barnsley CCG</td>
<td>Commissioner</td>
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<td>Name</td>
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<td>Dr Maria Reed</td>
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<td>Mary Riches</td>
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<td>Jane Rudge</td>
<td>Macmillan</td>
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<td>Martin Salt</td>
<td>Sheffield Teaching Hospitals</td>
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<td>Sue Sanderson</td>
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<td>Chris Shaw</td>
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<td>Executive, Service and Development</td>
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<td>Stephen Stewart</td>
<td>Sheffield Teaching Hospitals</td>
<td>Enterprise Architecture and Technology Strategy Team</td>
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<td>Georgia Thompson</td>
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<td>Shirley Thompson</td>
<td>Sheffield Teaching Hospitals</td>
<td>Manager of South Yorkshire Education in Cancer &amp; LTCs</td>
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<td>Rebecca Trevor</td>
<td>Sheffield City Council</td>
<td>Physical Activity in Cancer Representative</td>
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<td>Sue Wake</td>
<td>Rotherham Foundation Trust</td>
<td>Macmillan Project Manager</td>
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<td>Hayley Williams</td>
<td>NHS Sheffield</td>
<td>Programme Manager</td>
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Annex 2 Stakeholder interview topic guides

A2.1 Area lead interview topic guide

This guide is for use with area leads, who should have a thorough operational knowledge of local projects which form part of the overall Macmillan Cancer Survivorship Programme. Area leads should also have views regarding the strategic context of local projects, within their organisation, North Trent*, and also the broader context of the cancer survivorship agenda. The interviews should be used to gather reflections of how the local projects and the larger programme have been implemented, and the impact of projects on outcomes for: people affected by cancer; healthcare professionals; provider organisations; and the local health and social care system.

The purpose of these interviews is to;

■ generate learning about how colorectal cancer survivorship service improvement has been designed and implemented;
■ gather evaluative evidence from the local projects; and
■ inform the overall evaluation of the programme.

These interviews should be undertaken over the telephone. Interviews should last around 40-60 minutes. Information gained will feed into the Final Report for the Macmillan Cancer Survivorship Programme. Reports will be made available at the discretion of Macmillan; findings may also be shared and fed back in dissemination events planned for the end of the programme.

The guide is semi-structured and contains a set of key issues to cover, with related probes and prompts. Not all the questions will be relevant for every interviewee. Please tailor this guide accordingly, ensuring that the broad topics are covered. Not all interviewees will understand the changes they are involved in, in terms of a broader ‘programme’; therefore please tailor questions according to the services that interviewees are involved in. Before interviews, please review the stakeholder ‘matrix’ in order to check which services your interviewees are involved in.

Interviewees are being interviewed on the basis that whilst individual organisations may be identified, no individuals will be and that all quotations used will be made anonymous. This should be made clear at the start of the interview, and permission to record interviews should also be requested.

Instructions to interviewers and prompts are marked in purple text.

*For the purposes of this evaluation, North Trent is defined as the following areas: Sheffield; Barnsley; Doncaster; and Rotherham

A) Background and rationale

1. Please describe your job title, role, and how you came to be involved in the survivorship programme.

2. Please summarise the local project(s) on colorectal cancer survivorship, which you have been involved in.

   Probes: How was the project(s) you are involved in set up? Who developed the project(s) and did this change over time? Has this included trialling the following: recovery package; treatment summary; health and wellbeing support; 1-2-1 support; remote monitoring; telehealth; risk stratified pathways; workforce education and development; working through cancer/supporting return to work; supporting physical activity and cancer; cancer care reviews; rehabilitation.

3. Please describe the rationale for your project(s).

   Probes: Why was there a need for it/them? What evidence is there of this need?
B) Design and Implementation

4. Please describe the main activities of the project(s).

5. Describe the key challenges you have faced in the implementation of your project(s)? How have these been overcome?
   Probes: what were the barriers to delivering your project(s) effectively? What role did different stakeholders (e.g. senior managers/delivery staff) have in overcoming these challenges?

6. What has worked well?
   Probes: what were the key facilitators for these successes? What role did different stakeholders (e.g. senior managers/delivery staff) have in contributing to these successes?

7. What have been the lessons arising from implementing your project(s)? How have these impacted on your project(s)?

8. What have been the main outputs of the project(s)?
   Probes: is the focus on ‘simple’ outputs, such as the number of patients or a new tool; or are we looking at more complex outputs, such as revised survivorship pathways?

9. What were the benefits (or challenges) of these projects being part of a larger programme supported by Macmillan?
   Probes: Was learning shared across projects and localities? What ‘added value’ was there in being part of a larger programme? What would have happened if the project was delivered in isolation or if there wasn’t a wider survivorship programme?

C) Outcomes

Use these questions to focus the discussion on effects of the project(s) in terms of outcomes, and longer term impacts. Explore the barriers and facilitators in terms of contextual factors, and how these might impact on the success of the project(s) and overall programme. Tease out as many detailed examples as possible. (Note, not all projects will seek an effect in each of these areas, explore / leave topics as appropriate).

Were specific outcome measures set for the project(s)?
   Probes: What process was implemented to identify these outcomes? How are they being measured? What PROMs have been put in place?

10. What have been the main outcomes of your project(s) so far, at the level of:
   i) PABC?
      Probes: what enabling factors can lead to better recovery, survivorship/follow-up experiences, quality of life, and self-management for patients? What barriers may prevent the same outcomes? Has the programme impacted on earlier parts of the pathway, for example on prevention and earlier detection? Have there been outcomes in terms of supporting people to get back to work sooner? If so, approximately how many patients have been helped (per month) before and after the interventions were implemented?

   ii) Health care professionals?
      Probes: What knowledge gains have been acquired since the project(s) began – for those funded by the programme, and for those receiving training? What outcomes have there been for the wider workforce (e.g. social care, voluntary support agencies)? Have there been improvements in relationships/communication between HCPs from different teams/organisations? How has this helped improve follow-up pathways and survivorship? What are the requirements for ongoing professional development of these HCPs?

   iii) The health and social care organisations involved?
Probes: What have been the outcomes for secondary and primary care? What have been outcomes for social care and for support agencies in the voluntary sector? Has consultant time been saved/directed to more complex cases? Have there been cost savings to organisations? Has resource been used more efficiently? Has demand for services been better managed? Has organisational culture change been observed? Have there been changes in the priorities related to cancer care?

iv) Wider system level changes?

Probes: Have cost savings/more efficient use of resource been demonstrated across the local system? What have been the implications of this for coordination of services? Have there been changes in how organisations work together or communicate?

11. Were there any unintended outcomes of the project(s)?

Probes: Were these outcomes positive or negative for the project? In what ways?

12. How might your project and the programme contribute to the overall system change required for transforming cancer follow-up services within a survivorship model? What else might be required?

Probes: What else will be needed to further push the survivorship agenda along? What are the policy developments that are needed to support on-going progress beyond the life of the programme?

D) Sustainability and recommendations

Use these final questions to gain an understanding of the future of cancer survivorship in the locality and broader programme area (Sheffield, Barnsley, Doncaster, Rotherham). What else is needed to improve the implemented models, and how might Macmillan ensure that the programme is a success?

13. What are the most important lessons you have drawn from your project(s) in relation to providing services for people living with and beyond cancer?

14. What are your reflections on the added value of Macmillan’s involvement?

Probes: have they helped to develop the survivorship agenda locally? To what extent have they stimulated activity that would not otherwise have happened?

15. What plans have you made for sustaining the project(s) post-Macmillan funding?

Probes: What measures have taken place already? What further measures are planned? How established are project links to key stakeholders who can be instrumental in supporting continued progress after the programme?

16. What do you think will be required to move your project forward into sustained improvements in the quality of cancer follow-up services, both in and outside your organisation?

Probes: What else is required to mainstream service improvement in this area? What steps are being taken to maximise the chances of success, for example by on-going sharing of project success in the wider policy context. How likely is it that good practice will spread beyond colorectal cancer/project sites, and how can this spread be facilitated?

17. What (if any) recommendations do you have for Macmillan?

Probes: How can they ensure that the programme is a success? What are the external factors which might present challenges or barriers that they should be mindful of?

18. Finally, do you have any further points you would like to make in relation to the topics discussed, or are there any other issues you would like to raise?

Thank the interviewee for their time and close.

A2.2 Interview topic guide for staff (Secondary care)

This guide is for use with secondary care staff in Sheffield, who are involved in the programme. In
most cases this will be healthcare professionals and service managers. Interviewees may be funded by Macmillan in a new healthcare professional role, or they may work closely with new services and pathways implemented by the programme. Staff should therefore have an operational knowledge of the projects/elements of the programme they are involved in. They should also have some understanding of the context and background, although may not have a detailed knowledge of how the programme was designed and commissioned.

Broadly speaking the interviews should be used to gauge reflections on their own role in the programme, and how they see this benefitting PABC, organisations and systems, and their own development. The purpose of these interviews is therefore to use them to evaluate the programme, in terms of progress and outcomes, and expected impact.

This topic guide should be used for both the face-to-face, and the telephone interviews. Interviews should last around 30-40 minutes. Information gained will be used to evaluate the overall programme, and will feed into the Final Report for Macmillan.

The guide is semi-structured and contains a set of key issues to cover, with related probes and prompts.

Not all the questions will be relevant for every interviewee. Please tailor this guide accordingly, ensuring that the broad topics are covered. Not all interviewees will understand the changes they are involved in, in terms of a broader ‘programme’; therefore please tailor questions according to the services that interviewees are involved in.

Interviewees are being interviewed on the basis that whilst individual organisations may be identified, no individuals will be and that all quotations used will be made anonymous. This should be made clear at the start of the interview, and permission to tape interviews should also be requested.

Instructions to interviewers and prompts are marked in purple text.

A) Background & role

Use these questions to establish the background of the interviewee, and their involvement in the colorectal cancer survivorship programme.

1. Please describe your job title, role, and how you came to be involved in the survivorship programme.

Probes: What is your role in relation to colorectal cancer? Is this a new role? How long have you had an interest/worked in cancer survivorship?

2. Please describe the elements of the programme which you have been involved in.

Probes: How was the project(s) you are involved in set up? Who developed the project(s) and did this change over time? Has this included trialling the following: recovery package; treatment summary; health and wellbeing support; 1-2-1 support; remote monitoring; telehealth; risk stratified pathways; workforce education and development; working through cancer/supporting return to work; supporting physical activity and cancer; cancer care reviews; rehabilitation.

3. Please describe your understanding of the purpose behind the programme – why was it needed?

Probes: Why is it important? Was it established in response to a particular problem?

B) Implementation

Use these questions to discuss how the revised pathways have been implemented, how they changed care and support, and how applicable the risk stratification model for follow-up care is in practice.

4. Please describe the changes implemented by the revised pathways.
Probes: How is the programme redesigning pathways for patients? How effectively were the key features of the revised pathways implemented – e.g. Holistic Needs Assessment; treatment summaries; health and wellbeing days; HCP training?

5. What are your views on the processes for risk stratification of patients onto the follow-up pathways?

Probes: What were the key criteria that stratification was based on? What risk stratification tools were used, and what are your reflections on these? How clear is the differentiation between the pathways?

6. What are your views on earlier transfer to primary care for Level 1 and 2 patients?

Probes: How prepared were primary care for earlier transfer of care? What were the training needs and how were these identified? What training and development took place with primary care in relation to the revised pathways, and how was this received?

7. How is care for Level 3 patients different under the revised pathways?

Probes: Is support more intensive than the previous pathway? What are the key contact points with secondary care, and how are these different? What other new processes have been introduced and how effective are these – e.g. rapid access back into care.

8. Describe the key challenges you have faced in implementing the changes to the pathways? How have these been overcome?

Probes: What were the barriers to delivering different parts of the programme effectively?

C) Outcomes

9. What have been the main effects of the programme so far, at the level of:

i) PABC?

Probes: what enabling factors can lead to better recovery, survivorship/follow-up experiences, quality of life, and self-management for patients? What barriers may prevent the same outcomes? Has the programme impacted on earlier parts of the pathway, for example on prevention and earlier detection? Have there been outcomes in terms of supporting people to get back to work sooner? If so, approximately how many patients have been helped (per month) before and after the interventions were implemented? Were there any negative effects on patients – e.g. anxiety about being discharged sooner?

ii) Health care professionals?

Probes: What knowledge gains have been acquired since the project(s) began – for those funded by the programme, and for those receiving training? How has this helped improve follow-up pathways and survivorship? What are the requirements for ongoing professional development of these HCPs? Have there been improvements in relationships/communication between HCPs from different teams/organisations?

iii) The organisations involved?

Probes: What have been the outcomes for secondary and primary care? Has consultant time been saved/directed to more complex cases? Roughly how many days of consultant time have been saved per month? Has resource been used more efficiently? Has demand for services been better managed? Has organisational culture change been observed? Have there been changes in the priorities related to cancer care?

iv) Wider system level changes?

Probes: Have cost savings/more efficient use of resource been demonstrated across the local system? What have been the implications of this for coordination of services?
D) Sustainability and recommendations

Use these final questions to gain an understanding of the future of cancer survivorship in North Trent. What else is needed to improve the revised pathways, and how might Macmillan ensure that the programme is a success?

10. What are the most important lessons you have drawn from the programme in relation to providing services for people living with and beyond cancer?

11. What are your reflections on the added value of Macmillan’s involvement?
   Probes: have they helped to develop the survivorship agenda locally? To what extent have they stimulated activity that would not otherwise have happened?

12. What else do you think will be required to move this work forward into sustained improvements in the quality of cancer follow-up services, both in Sheffield and across North Trent?
   Probes: What else is required to extend these pathways? What steps are being taken to maximise the chances of success, for example by on-going sharing of success in the wider policy context. How likely is it that good practice will spread beyond colorectal cancer/project sites, and how can this spread be facilitated?

13. What (if any) recommendations do you have for Macmillan in improving services for people living with and beyond cancer?
   Probes: How can they ensure that the programme is a success? What are the external factors which might present challenges or barriers that they should be mindful of?

14. Finally, do you have any further points you would like to make in relation to the topics discussed, or are there any other issues you would like to raise?

Thank the interviewee for their time and close
This guide is for use with primary care staff in Sheffield, who have seen transfer of care to them sooner than what they did before the programme was implemented. Interviewees may have worked in new ways since the revised pathways were implemented – for example by supporting follow-up for colorectal cancer patients 2 or 3 years after the end of treatment (rather than 5 years after). These staff may not necessarily have a detailed knowledge of the programme – and will have seen only a very small number of relevant patients – but should be aware of their own changed role, and how this has impacted on patient care. They should also have some understanding of the context and background.

Broadly speaking the interviews should be used to gauge reflections on their own role in the programme, how they see risk stratified pathways impacting on primary care, and how this may benefit PABC and their own development. The purpose of these interviews is therefore to use them to evaluate primary care involvement with the programme in terms of progress and outcomes, and expected impact.

This topic guide should be used for telephone interviews. Interviews should last around 30-40 minutes. Information gained will be used to evaluate the overall programme, and will feed into the final report for Macmillan.

The guide is semi-structured and contains a set of key issues to cover, with related probes and prompts. Not all the questions will be relevant for every interviewee. Please tailor this guide accordingly, ensuring that the broad topics are covered. Not all interviewees will understand the changes they are involved in, in terms of a broader ‘programme’; therefore please tailor questions according to the services that interviewees are involved in.

Interviewees are being interviewed on the basis that whilst individual organisations may be identified, no individuals will be and that all quotations used will be made anonymous. This should be made clear at the start of the interview, and permission to tape interviews should also be requested.

Instructions to interviewers and prompts are marked in purple text.

A) Background & role

Establish background and role of interviewee.

1. Please describe your job title, role, and how you came to be involved in the survivorship programme.

2. Please describe the elements of the programme which you have been involved in.

Probes: Has this included trialling the following: treatment summary; health and wellbeing support; workforce education and development; supporting physical activity and cancer; cancer care reviews; rehabilitation.

3. If you have an understanding of the broader programme, please describe its purpose – why was it needed?

Probes: Why is it important? Was it established in response to a particular problem?

B) Implementation

Use these questions to discuss how the revised pathways have been implemented, how they changed care, and how applicable the risk stratification model for follow-up care is in practice.

4. Please describe the changes implemented by the programme/revised pathways. What has this meant for your role in primary care?
Probes: How is the programme redesigning pathways for patients? How different is the structured primary care pathway to what you were doing before the programme? Did you monitor patients in the same way? What is different now? How important is it for patients to have follow-up care closer to home?

5. What are your reflections on the risk stratification model for patients on follow-up pathways?
Probes: What are the benefits for different groups of patients? What are the implications for primary and secondary care? Can appropriate distinctions between patients be made in terms of risk?

6. How useful have you found the treatment summary?
Probes: Do you use it/does it make your job easier? Does it provide the right information? What if anything is missing? Are you broadly satisfied with the process/format? If not, how can it be improved?

7. What has your experience of conducting the cancer care review been?
Probes: How long does it take? Do you find it useful for the patient/your practice?

8. How effective is earlier transfer to primary care for Level 1 and 2 patients?
Probes: How prepared is primary care for earlier transfer of care? What were the training needs and how were these identified? What training and development took place with primary care in relation to the revised pathways, and how was this received? What further needs are there, and how might these be met?

9. Describe the key challenges you have faced in the implementation of your role as part of the structured follow-up pathways? How have these been overcome?
Probes: What were the barriers to delivering different parts of the structured follow-up pathways effectively?

10. What has worked well so far?
Probes: what were the key facilitators for these successes?

11. What have been the key lessons from implementing the structured follow-up pathways? How have these impacted on your role within the programme?

12. How have you been prepared for, and supported in your role?
Probes: Please describe the training you were given, and any further plans for your development? Did this meet your needs, what else would have been useful? Would you have received similar training without this programme? How did you seek out further development for yourself?

C) Outcomes and expected impact

13. What have been the main effects of the programme so far, at the level of:

   i) PABC?
   Probes: what enabling factors can lead to better recovery, survivorship/follow-up experiences, quality of life, and self-management for patients? What barriers may prevent the same outcomes? Has the programme impacted on earlier parts of the pathway, for example on prevention and earlier detection?

   ii) Health care professionals?
   Probes: What knowledge gains have been acquired in primary care since the programme began? How has this helped improve follow-up pathways and survivorship? What are the requirements for ongoing professional development of different professional groups? Have there been improvements in relationships/communication between HCPs from different teams/organisations?

   iii) The organisations involved?
   Probes: What have been the outcomes for secondary and primary care? Are there likely to have been cost savings to organisations? If so where will these have come
from? Has resource been used more efficiently? Has demand for services been better managed? Has organisational culture change been observed? Have there been changes in the priorities related to cancer care?

iv) Wider system level changes?

Probes: Have cost savings/more efficient use of resource been demonstrated across the local system? What have been the implications of this for coordination of services?

D) Sustainability and recommendations

Use these final questions to gain an understanding of the future of cancer survivorship in North Trent. What else is needed to improve the revised pathways, and how might Macmillan ensure that the programme is a success?

14. What are the most important lessons you have drawn from the programme in relation to providing services for people living with and beyond cancer?

15. What are your reflections on the added value of Macmillan’s involvement?

Probes: have they helped to develop the survivorship agenda locally? To what extent have they stimulated activity that would not otherwise have happened?

16. What else do you think will be required to move this work forward into sustained improvements in the quality of cancer follow-up services, both in Sheffield and across North Trent?

Probes: What else is required to extend these pathways? What steps are being taken to maximise the chances of success, for example by on-going sharing of success in the wider policy context. How likely is it that good practice will spread beyond colorectal cancer/Sheffield, and how can this spread be facilitated?

17. What (if any) recommendations do you have for Macmillan?

Probes: How can they ensure that the programme is a success? What are the external factors which might present challenges or barriers that they should be mindful of?

18. Finally, do you have any further points you would like to make in relation to the topics discussed, or are there any other issues you would like to raise?

Thank the interviewee for their time and close
A2.4 Interview topic guide for staff (Other)

This guide is for use with non-healthcare staff who are involved in the programme. Interviewees may be drawn from the voluntary or social care sectors. They may not necessarily have a detailed knowledge of the programme, but will have insights about the impact of it on their services. They should also have some understanding of the context and background.

Broadly speaking the interviews should be used to gauge reflections on their own role in the programme, how they see this benefitting PABC, and implications for organisations in their sector. The purpose of these interviews is therefore to use them to evaluate the programme, in terms of progress and outcomes, and expected impact in terms of how the programme works with broader support services.

This topic guide should be used for telephone interviews. Interviews should last around 30-40 minutes. Information gained will be used to evaluate the overall programme, and will feed into the final report for Macmillan.

The guide is semi-structured and contains a set of key issues to cover, with related probes and prompts. Not all the questions will be relevant for every interviewee. Please tailor this guide accordingly, ensuring that the broad topics are covered. Not all interviewees will understand the changes they are involved in, in terms of a broader ‘programme’; therefore please tailor questions according to the services that interviewees are involved in.

Interviewees are being interviewed on the basis that whilst individual organisations may be identified, no individuals will be and that all quotations used will be made anonymous. This should be made clear at the start of the interview, and permission to tape interviews should also be requested.

Instructions to interviewers and prompts are marked in purple text.

A) Background & role

Establish background and role of interviewee.

1. Please describe your job title, role, and how you came to be involved in the survivorship programme.

2. Please describe your understanding of the purpose behind the changes made to services for patients living with and beyond colorectal cancer – why was it needed?

B) Implementation

Use these questions to discuss how the revised pathways have been implemented, how they changed care and support, and how applicable the risk stratification model for follow-up care is in practice.

3. Please describe the changes implemented by the programme/revised pathways for patients living with and beyond colorectal cancer. What has this meant for your role?

   Probes: How is the programme redesigning pathways for patients? Has your practice changed as a result of the programme? If so how? Has there been an increase in demand for wider services? Has access to wider services improved?

4. What are your reflections on the risk stratification model for patients on follow-up pathways?

   Probes: What are the benefits for different groups of patients? What are the implications for wider support services? Is there a different role for organisations delivering wider support, depending on which risk category (low-medium-high) a patient is in?

5. Describe the key challenges you have faced in the implementation of your role as part of the programme? How have these been overcome? What has worked well so far?
Final Report

Probes: What were the barriers to supporting patients effectively in the revised pathway? How are these barriers different to what was happening anyway? What were the key facilitators for these successes?

6. What have been the key lessons from supporting PABC as part of the programme? How have these impacted on your role within the programme, and more broadly?

7. How have you been prepared for, and supported in your role?

Probes: Please describe any information/briefings/training you were given, and any further plans for increasing your knowledge and understanding of the programme? Did this meet your needs, what else would have been useful?

C) Outcomes and expected impact

8. What have been the main effects of the programme so far, at the level of:
   i) PABC?

   Probes: what enabling factors can lead to better recovery, survivorship/follow-up experiences, quality of life, and self-management for patients? What barriers may prevent the same outcomes? Has the programme impacted on earlier parts of the pathway, for example on prevention and earlier detection?

   ii) Professionals working in the health/social care, voluntary, and community sectors?

   Probes: What knowledge gains have been acquired since the programme began? How has this helped improve follow-up pathways and survivorship? What are the requirements for ongoing professional development of different professional groups? Have there been improvements in relationships/communication between professionals (including HCPs) from different teams/organisations?

   iii) The organisations involved?

   Probes: What have been the outcomes for organisations delivering wider support services? Have there been any implications in terms of generating income? Has organisational culture change been observed? Have there been changes in the priorities related to cancer care and support?

   iv) Wider system level changes?

   Probes: Have cost savings/more efficient use of resource been demonstrated across the local system? What have been the implications of this for coordination of services?

D) Sustainability and recommendations

Use these final questions to gain an understanding of the future of cancer survivorship in North Trent. What else is needed to improve the revised pathways, and how might Macmillan ensure that the programme is a success?

9. What are the most important lessons you have drawn from the programme in relation to providing services for people living with and beyond cancer?

10. What are your reflections on the added value of Macmillan’s involvement?

   Probes: have they helped to develop the survivorship agenda locally? To what extent have they stimulated activity that would not otherwise have happened?

11. What else do you think will be required to move this work forward into sustained improvements in the quality of cancer follow-up services, both in Sheffield and across North Trent?

   Probes: What else is required to extend these pathways? What steps are being taken to maximise the chances of success, for example by on-going sharing of success in the wider policy context. How likely is it that good practice will spread beyond colorectal cancer/Sheffield, and how can this spread be facilitated?

12. What (if any) recommendations do you have for Macmillan?
Probes: How can they ensure that the programme is a success? What are the external factors which might present challenges or barriers that they should be mindful of?

13. Finally, do you have any further points you would like to make in relation to the topics discussed, or are there any other issues you would like to raise?

Thank the interviewee for their time and close

A2.5 Interview topic guide for strategic stakeholders

This guide is for use with strategic stakeholders, who may not necessarily have a thorough
operational knowledge of the Macmillan Cancer Survivorship Programme. They should have a detailed understanding of the local context and strategic priorities in relation to the cancer survivorship agenda.

The interviews should be used to gather reflections on how the programme fits within this context, how it responds to local and national policy, and the impact it has had in terms of strategic influence, as well as outcomes for PABC, HCPs, organisations, and the local health and social care system.

These interviews should be undertaken over the telephone. Interviews should last around 40-60 minutes. Information gained will feed into the Final Report for the Macmillan Cancer Survivorship Programme. Reports will be made available at the discretion of Macmillan; findings may also be shared and fed back in dissemination events planned for the end of the programme.

The guide is semi-structured and contains a set of key issues to cover, with related probes and prompts. Not all the questions will be relevant for every interviewee. Please tailor this guide accordingly, ensuring that the broad topics are covered. Not all interviewees will understand the changes they are involved in, in terms of a broader ‘programme’; therefore please tailor questions according to the services that interviewees are involved in.

Interviewees are being interviewed on the basis that whilst individual organisations may be identified, no individuals will be and that all quotations used will be made anonymous. This should be made clear at the start of the interview, and permission to record interviews should also be requested.

Instructions to interviewers and prompts are marked in purple text. Interviews will need tailoring; not all interviewees will be able to answer all questions.

A) Background & role

Establish background and role of interviewee.

1. Please describe your understanding of the purpose behind the programme – why was it needed? Why did you support the programme (or not)?
   
   Probes: How will it improve care and support for PABC? Why is it important? Was it established in response to a particular problem? What evidence was there for the need for this programme?

B) Design and Implementation

Use these questions to discuss how the revised pathways were designed and implemented, how they changed care and support, and how applicable the risk stratification model for follow-up care is in practice.

2. Please describe your understanding of the aims and objectives of the programme.

3. How is survivorship being supported by the programme?
   
   Probes: How is the programme redesigning services/pathways for patients? How is it delivering new support services? How is it delivering services differently?

4. What are your reflections on the risk stratification model for patients on follow-up pathways?
   
   Probes: What are the benefits for different groups of patients? What are the implications for different sectors (primary and secondary care/social care/voluntary sector)? What should be the key criteria that stratification is based on? Can appropriate distinctions between patients be made in terms of risk?

5. How useful was the ‘Routes From Diagnosis’ work in shaping the programme?
   
   Probes: Was this work meaningfully translated to the local context? Has this work remained a focus of the programme?

6. Describe the key challenges faced in the implementation of the programme? How have these been overcome? What has worked well so far?
Probes: What were the barriers to delivering different parts of the programme effectively? What were the key facilitators for these successes?

C) Outcomes and expected impact

7. What have been the main effects of the programme so far, at the level of:

i) PABC?

Probes: What enabling factors can lead to better recovery, survivorship/follow-up experiences, quality of life, and self-management for patients? What barriers may prevent the same outcomes? Has the programme impacted on earlier parts of the pathway, for example on prevention and earlier detection? Have there been outcomes in terms of supporting people to get back to work sooner? If so, approximately how many patients have been helped (per month) before and after the interventions were implemented?

ii) Health care professionals?

Probes: What knowledge gains have been acquired since the project(s) began – for those funded by the programme, and for those receiving training? How has this helped improve follow-up pathways and survivorship? What are the requirements for ongoing professional development of these HCPs? Have there been improvements in relationships/communication between HCPs from different teams/organisations?

iii) The organisations involved?

Probes: What have been the outcomes for secondary and primary care? Has consultant time been saved/directed to more complex cases? Are there likely to have been cost savings to organisations? If so where will these have come from? Has resource been used more efficiently? Has demand for services been better managed? Has organisational culture change been observed? Have there been changes in the priorities related to cancer care?

iv) Wider system level changes?

Probes: Have cost savings/more efficient use of resource been demonstrated across the local system? What have been the implications of this for coordination of services? What does ‘better’ care in relation to more coordinated care for colorectal patients look like? Have new models of care enhanced service integration and coordination?

8. Has the programme contributed to strategic developments in Sheffield and North Trent?

Probes: Has it influenced the way that cancer survivorship is understood? Has the programme mobilised strategy development for colorectal cancer or other cancers?

D) Sustainability and recommendations

Use these final questions to gain an understanding of the future of cancer survivorship in North Trent. What else is needed to improve the revised pathways, and how might Macmillan ensure that the programme is a success?

9. What are the most important lessons you have drawn from the programme in relation to providing services for people living with and beyond cancer?

10. What are your reflections on the added value of Macmillan’s involvement? What are your views on the partnership with Macmillan for this programme?

Probes: have they helped to develop the survivorship agenda locally? To what extent have they stimulated activity that would not otherwise have happened?

11. What plans have been made for sustaining the new pathways post-Macmillan funding?

Probes: What measures have taken place already? What further measures are planned? How established are links to key stakeholders who can be instrumental in supporting continued progress after the programme? Will the new posts supported by Macmillan be sustained. If so, how?
12. What else do you think will be required to move this work forward into sustained improvements in the quality of cancer follow-up services, both in Sheffield and across North Trent?

*Probes: What else is required to extend these pathways? What steps are being taken to maximise the chances of success, for example by on-going sharing of success in the wider policy context. How likely is it that good practice will spread beyond colorectal cancer/project sites, and how can this spread be facilitated?*

13. What (if any) recommendations do you have for Macmillan?

*Probes: How can they ensure that the programme is a success? What are the external factors which might present challenges or barriers that they should be mindful of?*

14. Finally, do you have any further points you would like to make in relation to the topics discussed, or are there any other issues you would like to raise?

*Thank the interviewee for their time and close*
Annex 3  Peer evaluation research tools

Instructions to peer evaluators

This is a topic guide to help you in your interviews with people affected by cancer. As we discussed in your training you will be interviewing people who have received treatment for colorectal cancer, and have now been discharged from the hospital. You may also be interviewing family members or carers of these former patients. These patients have no outstanding clinical issues to address in relation to cancer, and will be in one of the following groups for their remaining ‘follow-up’ care:

1. **Supported self-management** – patients in this group are being monitored by their GPs. This includes regular blood tests without seeing the GP in person.

2. **Shared care, with follow-up in primary care** – patients in this group are also being monitored by their GP practices. This includes regular blood tests, and also a face-to-face review with the GP or practice nurse.

We would like you to have a conversation with the people you are interviewing. Remember, we want to know about their views of the care they received **since the end of treatment and hospital follow-up**. They may talk about their treatment as well, but this is not the main focus of these interviews. We would like you to cover the following topics in your interviews:

- **Background** – finding out about the care the person has received before being discharged is a way of starting the conversation, a sort of ‘warming up’ for the rest of the interview.

- **End of treatment at the hospital** – this topic helps focus the interview on what we are really interested in. To find out about experiences of care after being discharged from hospital, we want to know what happened when treatment ended.

- **Care and support after discharge** – questions in this topic should be mainly about experiences of care and support from the GP, community services, and any support from charitable organisations, such as the Cancer Support Centre and AgeUK.

- **How services worked together** – in this topic we are interested in how all the different care and support givers worked together, and the extent to which the interviewees thought that their care was ‘joined up’.

- **Outcomes** – in these questions, we want to know specifically how the care and support your interviewees experienced after being discharged from hospital helped them (if at all).

- **Recommendations** – finally these interviews are important for finding out how we can improve support and care in the future. We want to know what interviewees think could improve the way they were supported after their treatment and follow-up ended in the hospital.

This guide contains questions and ‘probes’ under each topic. Please try and cover every topic, but you do not have to use every probe; this is a list which might help you to guide the conversation, or to encourage your interviewee to talk in more detail.
The interviews should be conducted sensitively. They should be conducted in person, and if the interviewee wishes, in the presence of another person (e.g. a family member, support worker). Interviews should last around an hour. Here are a few things that you need to remember at the start of the interview:

1) Please make sure that the interviewee has read the information sheet and signed the consent form.
2) In particular, please ensure that she or he fully understands that they can end the interview at any stage, even after it has started.
3) You should also tell them that the interviews are anonymous. This means that when we write any reports based on the findings, we may identify organisations (such as the hospital), but that we will not use their name. We may use some of their quotations but we won’t say where these came from.
4) Ask for permission to record interviews. If the interviewee does not wish for the interview to be recorded than thorough notes should be taken instead.

Questions

Topic 1: Background

Use this topic to find out how long ago treatment ended, and when the patient was discharged from hospital follow-up? When was their last appointment at the hospital?

1. Please describe the care and support that you received before being discharged from hospital.

   Probes: Did you receive a ‘care plan’ at any stage? Did you attend a health and wellbeing day?

2. Please describe the support your family members or carer(s) received before you were discharged from hospital.

Topic 2: End of treatment at the hospital

3. How did you feel when your treatment ended?

   Probes: What were your thoughts? Did you have any concerns? What was important to you at this stage? What did you need from the professionals and support agencies who were caring for/supporting you?

4. Please describe the support you received when your treatment ended, and your views on this support.

   Use this question to clarify if they have had a Holistic Needs Assessment (HNA) with the nurse before discharge, and if so to explore their experience of this. Remember: a HNA helps patients and healthcare professionals to work together to: identify people who need help, and to decide and plan how they can be helped by professionals, their friends and families, and themselves.

   Probes: Did your consultant/ nurse talk to you about what would happen next? Were you satisfied with the conversations you had? Did you see a nurse?

5. What were your care and support needs once your treatment had ended? Did you talk to anybody about these needs?

   Probes: Did you have a say in making decisions about your ongoing care and support needs? Was this useful/important to you?
6. At the point of discharge, how confident did you feel about your knowledge of where you could get further support?

Probes: What information were you given? Was this sufficient? What else might have been useful to know? Was there any information given for your family members or carer(s)?

**Topic 3: Care and support after discharge**

7. Please describe the care and support you have received since being discharged from the hospital? Where has this come from?

Probes: How did you access care and support services? What were the types of service you received, who were the main people involved in this care?

8. Please describe the support your family members or carer(s) have received since you were discharged from the hospital.

9. Please describe the contact you have had with your GP since your treatment and follow up at the hospital ended.

*Use this question to explore experiences of supported self-management, and shared care (follow-up by the GP).*

Probes: Was your GP sent a summary of the treatment you had in the hospital? Did she or he discuss this with you? Have you been in for blood tests, and have you been satisfied with the monitoring process? Have you seen the GP or a nurse for a review?

10. Were you given any information about or support to access other more informal forms of support – e.g. the Cancer Information and Support Centre; support to get back into work; practical support; information about exercise? Did you take up this support? Why/why not?

11. How well do you think your emotional / psychological support needs have been understood and met since discharge? Were you offered support in this area, and did you take this up?

**Topic 4: How did services work together?**

12. Did the main professionals and support agency workers who were responsible for your care communicate well between themselves and with you?

Probes: Please describe how the different organisations involved in your care worked together? Were you happy with the way that care was delivered by the different organisations/people involved? Did you feel that you had to repeat your ‘story’ at each organisation? Were services seamless?

13. Did you feel that you could re-access your professionals at the hospital if you needed to?

Probes: If you did re-access the hospital, how did you do this? Were you satisfied with the process? Did you see the person that you wanted to see?

14. How confident do you feel about asking the professionals who cared for you questions about any aspect of your care and support?
**Topic 5: Outcomes**

15. Has the care you received since your treatment ended helped you? If so, in what ways?

_Probe for outcomes re. knowledge of condition, confidence to self-manage, well-being, emotional help, physical health, return to work etc. Did you find planning for your ongoing needs with your nurse helpful? Did you find the health and wellbeing day you attended helpful?_

16. What else might have been helpful for you?

_Probes: Did you feel like you had any needs which weren’t met? Were you able to find all the support that you needed/would have found helpful? Did you find that you got the right support at the right time?_

**Topic 6: Recommendations**

17. Do you have any recommendations for improving the care you’ve received following the end of your treatment?

And finally, would you like to discuss anything else about the topics we have talked about?

**Thank the interviewee before ending the interview.**
A3.1 PABC information sheet

We would like to hear your views

Information sheet

What’s the project about?

Between 2013 and 2015, Macmillan Cancer Support is working with Sheffield Teaching Hospital NHS Trust to improve care provided to people living with bowel cancer, following the end of treatment. The services you used – both in the hospital and in your GP practice – are part of this work.

ICF is an independent research firm. We will be carrying out an evaluation to see whether and how care has improved. To help us do this, we are conducting short interviews with service users / their families. The interview will focus on your views and experiences of care and ways in which it could be improved.

What would I have to do?

If you would like to help, you would take part in an interview of about 30 minutes. A member of our team will ask you about your views and experiences of the care and support you received. If there is anything that you do not feel comfortable talking about, it is OK not to share this in the interview. The decision about what to share, or not, is yours. You are also free to stop the interview at any point, without giving a reason.

What will happen to the information I give?

We will ask your permission to record the interview so that we have a full record of what everybody said. We might also include things that you say in a written report which will be shared with Macmillan Cancer Support and Sheffield Teaching Hospital NHS Trust. It is possible we may also wish to use interview findings in the wider public domain (for e.g. on websites; in local events and conferences; or in the media). But we will not mention your name or anything that could identify you.
Participant consent form (face-to-face)

I have read the information sheet, or had it explained to me? YES  NO

I have had time to ask questions, and am happy with the answers? YES  NO

I understand what taking part in the project will involve? YES  NO

I agree that the interview can be recorded? YES  NO

I agree you can mention things that I say during interview, but not my name, in your report? YES  NO

I understand that I can stop taking part at any time (and do not have to say why I want to stop)? YES  NO

I agree to take part in the project? YES  NO

_______________________  ________________  ___________________________
Name of participant       Date          Signature

________________________  ________________  ___________________________
Name of person taking consent  Date          Signature
Dear

We are interested in your views about the services you have used in the hospital and at your GP practice. We want to know about your experiences since your treatment for bowel cancer ended at the hospital.

An independent evaluation company, ICF, has been asked by Macmillan Cancer Support to speak to people about their experiences. Your participation in the evaluation will contribute to improving services. We can only know how well services are running if we speak to the people who have used them.

Whether you take part or not is entirely your choice.

What will happen if you take part?

If you wish to take part you will be interviewed by a person who has also been affected by cancer. This person has been trained in interviewing. The interview will take place at the Cancer Support Centre over the next few weeks. The Cancer Support Centre is just behind Weston Park Hospital car park, at 23 Northumberland Road. A time which is convenient for you will be arranged for the interview.

You will receive a £25 shopping voucher as a thank you gift. Your travel expenses for getting to the Cancer Support Centre will also be reimbursed.

What to do next

If you would like to take part, please complete the slip below and return it in the stamped addressed envelope provided.

A researcher from ICF will then contact you to discuss the interview in more detail, and to arrange a time with you.

We thank you in advance,

Name ......................

Address ......................
Telephone number .................................

Email address .................................

I give permission for my contact details to be passed to the research company (ICF)

Signed .................................
### Annex 4  Cost of health and wellbeing day

<table>
<thead>
<tr>
<th>Numbers of Roadshow participants</th>
<th>Total cost of HWB Roadshow (rounded to nearest £)</th>
<th>Cost per head (rounded to nearest £)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£2,305.00</td>
<td></td>
</tr>
</tbody>
</table>

**Cost of colorectal follow-up outpatient appointment: £71**

- patients
  - 28  
  - £83
- carers
  - 15
- total patients and carers
  - 43  
  - £54
- stall holders
  - 25
- total participants
  - 68  
  - £34

*Source: Coy, J. (n.d.). Evaluation of the Health and Wellbeing Roadshow held on Monday 12th May 2014, p. 15*
## Annex 5  Sources of data used in economic analysis

<table>
<thead>
<tr>
<th>Type of information</th>
<th>Reason required</th>
<th>Value</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information for secondary care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unit cost of first consultant led follow-up appointment in secondary care setting</td>
<td>The unit cost of follow-up appointments in a secondary care setting was required to calculate the cost of providing colorectal follow-up in secondary care in both scenario 1 and 2.</td>
<td>£118</td>
<td>NHS, Monitor. National Tariff Payment System, 2014-2015</td>
</tr>
<tr>
<td>Unit cost of subsequent consultant led follow-up appointment in secondary care setting</td>
<td>The unit cost of follow-up appointments in a secondary care setting was required to calculate the cost of providing colorectal follow-up in secondary care in both scenario 1 and 2.</td>
<td>£71</td>
<td>NHS, Monitor. National Tariff Payment System, 2014-2015</td>
</tr>
<tr>
<td>Unit cost of a CT scan in secondary care</td>
<td>The unit cost of a CT scan was required to calculate the cost of providing colorectal follow-up pathway in both scenario 1 and 2.</td>
<td>£88</td>
<td>NHS, Monitor. National Tariff Payment System, 2014-2015</td>
</tr>
<tr>
<td>Unit cost of health and well-being event</td>
<td>The cost of the health and well-being event was required to calculate the cost of the care pathways provided in scenario 2. The health and well-being event was a daylong event which multiple patients on the care pathway can attend. The care pathway includes two such events each year.</td>
<td>£2,305</td>
<td>Management Information</td>
</tr>
<tr>
<td><strong>Information for primary care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unit cost of a primary care follow-up appointment for Level 1 patients</td>
<td>The unit cost of a follow-up appointment in a primary care setting was required to calculate the cost follow-up appointments in scenario 2.</td>
<td>£19</td>
<td>Project Service Specification</td>
</tr>
<tr>
<td>Unit cost of a primary care follow-up appointment for Level 2 patients</td>
<td>The unit cost of a follow-up appointment in a primary care setting was required to calculate the cost follow-up appointments in scenario 2.</td>
<td>£59</td>
<td>Project Service Specification</td>
</tr>
<tr>
<td>Unit cost for GP review of treatment and follow up information</td>
<td>The unit cost of a GP review was required to calculate the cost follow-up appointments in scenario 2.</td>
<td>£33</td>
<td>PSSRU (2014) Unit Costs of Health and Social Care.</td>
</tr>
<tr>
<td><strong>Information for voluntary sector</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of referrals to voluntary sector</td>
<td>The number of referrals to the voluntary sector was expected to be higher in scenario 2 than in scenario 1, therefore the number of referrals to the voluntary sector needed to be accounted for.</td>
<td></td>
<td>Information on colorectal contacts with Weston Park Cancer Information and support centre</td>
</tr>
<tr>
<td>Type of information</td>
<td>Reason required</td>
<td>Value</td>
<td>Source</td>
</tr>
<tr>
<td>---------------------</td>
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</tr>
<tr>
<td>Unit cost of voluntary sector care</td>
<td>As the number of referrals to the voluntary sector varied between scenarios, the cost to the voluntary sector was different in each scenario. Therefore the cost of a voluntary sector referral was needed.</td>
<td>£11</td>
<td>Annual Survey of Hours and Earnings (ASHE) 2014</td>
</tr>
<tr>
<td>Information for hospital transport</td>
<td>The proportion of patients who require hospital transport was required to estimate the cost to the health service of transporting patients to and from their outpatient appointments in secondary care. This was required for both scenario 1 and 2. The remaining patients make their own way to the appointments.</td>
<td>50%</td>
<td>PSSRU (2006) Unit Costs of Health and Social Care.</td>
</tr>
<tr>
<td>Unit cost of providing hospital transport to a patient</td>
<td>The cost of hospital transport for outpatients was required to estimate the cost to the health service of transporting patients to and from their outpatient appointments in secondary care. This was required for both scenario 1 and 2.</td>
<td>£60</td>
<td>PSSRU (2006) Unit Costs of Health and Social Care.</td>
</tr>
<tr>
<td>Information for employers</td>
<td>The employment rate was required to estimate the loss to employers due to patients and carers attending follow up appointments in scenarios 1 and 2.</td>
<td>60%</td>
<td>Annual Population Survey, 2014</td>
</tr>
<tr>
<td>Employment rate – general population</td>
<td>The employment rate was required to estimate the loss to employers due to patients and carers attending follow up appointments in scenarios 1 and 2.</td>
<td>8%</td>
<td>Annual Population Survey, 2014</td>
</tr>
<tr>
<td>Employment rate – treatment group</td>
<td>The employment rate was required to estimate the loss to employers due to patients and carers attending follow up appointments in scenarios 1 and 2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Output per employee</td>
<td>The output per employee was required to estimate the loss of output for employers due to patients and carers attending follow up appointments in scenarios 1 and 2.</td>
<td>£40,300 / year</td>
<td>Office for National Statistics (2014) GVA per filled job.</td>
</tr>
<tr>
<td>Information for patients and carers</td>
<td>The travel time to hospital was required to estimate the total time a patient needs to attend an outpatient appointment in secondary care in scenarios 1 and 2.</td>
<td>8 minutes</td>
<td>Accessibility Statistics, 2012</td>
</tr>
<tr>
<td>Average travel time to hospital</td>
<td>The travel time to hospital was required to estimate the total time a patient needs to attend an outpatient appointment in secondary care in scenarios 1 and 2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average travel time to GP surgery</td>
<td>The travel time to the GP surgery was required to estimate the total time a patient needs to attend an outpatient appointment in secondary care in scenario 2.</td>
<td>5 minutes</td>
<td>Accessibility Statistics, 2012</td>
</tr>
<tr>
<td>Average time patients spend waiting for outpatient appointment in hospital</td>
<td>The time a patient spends waiting in a hospital for their outpatient appointment was required to estimate the total time a patient needs to attend an outpatient appointment in secondary care in scenarios 1 and 2.</td>
<td>1 hour</td>
<td>NHS Choices, NHS inpatient survey (2011-12)</td>
</tr>
<tr>
<td>Average time patients spend waiting for a GP appointment in GP surgery</td>
<td>The time a patient spends waiting in a GP surgery for their appointment was required to estimate the total time a patient needs to attend an outpatient appointment in scenario 2.</td>
<td>12 minutes</td>
<td>GP patient survey, 2014</td>
</tr>
<tr>
<td>Duration of consultant led follow-up appointment in secondary care</td>
<td>The time a patient spends in their follow-up appointment was required to estimate the total time a patient needs to attend an outpatient appointment in secondary care in scenarios 1 and 2.</td>
<td>30 minutes</td>
<td>NHS choices</td>
</tr>
<tr>
<td>Type of information</td>
<td>Reason required</td>
<td>Value</td>
<td>Source</td>
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<tr>
<td>-------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Duration of GP led follow-up appointment for Level 1 patients</td>
<td>The time a patient spends in their follow-up appointment was required to estimate the total time a patient needs to attend an outpatient appointment in secondary care in scenario 2.</td>
<td>15 minutes</td>
<td>PSSRU (2014) Unit Costs of Health and Social Care.</td>
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<tr>
<td>Duration of GP led follow-up appointment for Level 1 patients</td>
<td>The time a patient spends in their follow-up appointment was required to estimate the total time a patient needs to attend an outpatient appointment in secondary care in scenario 2.</td>
<td>30 minutes</td>
<td>Project Service Specification</td>
</tr>
<tr>
<td>Value of time</td>
<td>A value of time was required to estimate the cost of time patients and carers spend attending follow-up appointments in scenarios 1 and 2.</td>
<td>£10</td>
<td>Arup and ITS (2014) Meta-Analysis Of Post-1994 Values Of Non-Work Travel Time Savings</td>
</tr>
</tbody>
</table>

**Additional information**

| Proportion of patients who require informal carers | The proportion of patients who require an informal carer was required to calculate the loss to employers and time spent attending outpatient appointments. | 30%     | Macmillan / Sheffield CCG                                                                         |
| Size of colorectal cancer follow-up care cohort  | The number of patients receiving follow-up care for colorectal cancer in Sheffield was needed to calculate the total cost of the care pathway in each scenario. It was particularly important as in scenario 2 patients are assigned to different care pathways which attract different costs. This means a comparison of unit costs was not appropriate. Information regarding the type of cancer patients had was also required to estimate the cost of the care pathway in scenario 2. | 195     | Macmillan / Sheffield CCG                                                                         |
| Proportion of patients who are Level 1, Level 2 and Level 3 patients | The proportion of patients who were referred to each care pathway in scenario 2 was required to estimate the cost of the care pathway in scenario 2. | L1 = 33% L2 = 2% L3 = 65% | Macmillan / Sheffield CCG                                                                         |
| Discount factors                                 | The discount factors were required to convert the monetary values for future years into present values.                                                                                                         |         | HM Treasury, (2013), Green Book                                                                   |
| GDP deflators                                    | The GDP deflators were required to inflate monetary values from previous years to 2014 values.                                                                                                                |         | HM Treasury, (2014), GDP deflators at market prices                                           |