

Living With and Beyond Cancer - Baseline Activity

January – March 2017



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Medical	Operations and Information	Specialised Commissioning
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Publications Gateway Reference: 08124

Document Purpose	Resources
Document Name	Living With and Beyond Cancer - Baseline Activity January – March 2017
Author	NHS England - National Cancer Programme
Publication Date	July 2018
Target Audience	CCG Clinical Leaders, CCG Accountable Officers, CSU Managing Directors, Care Trust CEs, Medical Directors, Directors of Nursing, NHS Trust Board Chairs, NHS England Regional Directors, NHS England Directors of Commissioning Operations, GPs, NHS Trust CEs
Additional Circulation List	
Description	This report sets out baseline activity data from January to March 2017 for Stratified Follow Up and Recovery Package interventions which are part of the Living With and Beyond Cancer commitments in the National Cancer Strategy. This is the first time national data of this type has been reported.
Cross Reference	N/A
Superseded Docs (if applicable)	N/A
Action Required	N/A
Timing / Deadlines (if applicable)	N/A
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Document Status

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Title: Living With and Beyond Cancer - Baseline Activity

Subtitle January – March 2017

Version number: 1.0

First published: 6 June 2018

Prepared by: Lesley Smith, Senior Programme Manager, Living With and Beyond Cancer

Classification: OFFICIAL

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1 Executive Summary

The independent Cancer Taskforce set an ambitious aim for the NHS to make significant progress in reducing preventable cancers, increasing cancer survival and improving patient experience and quality of life by 2020. Personalised follow up and support to help people live well with and beyond cancer is one of the cornerstones to creating world class cancer services. Cancer Alliances are leading ambitious transformational programmes to deliver Stratified Follow Up pathways and Recovery Package interventions for patients across England by 2020/21. This report covers activity in the period January to March 2017, prior to the availability of transformation funding for Cancer Alliances after April 2017.

In some areas, patients have been benefiting from a personalised approach to care and support for many years, whilst in others, roll out is still in its early stages. It is important that benefits for patients and equity of access are achieved; hence we need a better understanding of where variation exists, and how future progress should be measured and monitored in order to have consistent and regular reporting.

A survey of trusts was commissioned, which was the first ever national data collection on various aspects of Stratified Follow Up pathway and Recovery Package activity. It thus sets the baseline from which to measure progress on delivery of these commitments. Summary figures are shown in Figure 1.

The survey respondents provided valuable information on the barriers and enablers to implementation. It was also important to understand the situation with local data collection, to inform the development of national data standards and introduce routine measurement and analysis of Stratified Follow Up and Recovery Package activity.

This national report does not compare Alliances at this point in time, but future iterations will begin to do so, linking to the Cancer Alliances Data, Evidence and Analysis Service (CADEAS).

There was a good response rate to the surveys from most Cancer Alliances, indicating that when routine data collection is introduced that this should result in high data completeness.

1.1 Stratified Follow Up Pathways

Half of the trusts who responded to the Stratified Follow Up pathway survey had criteria/protocols in place for assigning breast cancer patients to supported self-managed follow up, and a third had them for colorectal and prostate cancer. This is a promising baseline from which to achieve the 2018/19 NHS planning target of 100% of trusts having breast cancer Stratified Follow Up pathway protocols and remote monitoring systems by March 2019. The expectation is that full coverage with colorectal and prostate Stratified Follow Up pathways will be achieved by 2020.

Trusts that had adopted Stratified Follow Up pathway criteria/protocols were, on average, assigning 49% to 67% of patients to self-managed follow up. Some trusts reported that where Stratified Follow Up pathways are in place, they are achieving a reduction in routine follow up appointments, thus allowing resources to be redeployed

(for example, to reduce cancer waiting times or to increase resource for complex patient follow up).

NHS England, Cancer Alliances, trusts and other stakeholders will be giving greater focus to tackling the barriers that exist to introducing Stratified Follow Up pathways for breast, colorectal and prostate cancer patients, such as commissioning, digital systems and clinical engagement. All stakeholders should continue to share learning about the barriers and enablers (for example, from the Alliance-level baseline reports), as well as understanding the situation with implementation with rarer cancers, as this will help to accelerate progress.

1.2 Recovery Package

The survey found there was variable, but in some places, extensive use of different Recovery Package interventions in January to March 2017. Overall, there are positive signs that Recovery Package implementation is well underway, and that this provides ample opportunity for stakeholders to learn from peers who already have good experience with the interventions.

- Holistic Needs Assessments (HNAs) were reported as being used by 77% of trusts for patients within at least one cancer type Multidisciplinary Team (MDT). Overall, an estimated 31% of patients had an HNA, with the highest reported rate being 45% for breast cancer patients.
- Care Planning was reported by 58% of trusts for patients within at least one MDT. An estimated 15% of patients had a Care Plan, with the highest reported rate being 24% for breast cancer patients.
- Treatment Summaries were reported as being used by 53% of trusts within at least one MDT. Overall, an estimated 8% of patients had a treatment summary, with the highest reported rate being 37% for sarcoma patients.
- An estimated 95% of trusts reported delivering, referring patients to, or providing written information for, Health and Well-being support within at least one MDT, with the highest reported rate being 92% for breast cancer patients.

These figures, while likely to be under-estimates due to under-reporting, indicate that Care Planning and Treatment Summaries are where more attention is needed to achieve full implementation.

NHS England, Cancer Alliances, trust and other stakeholders will be giving greater focus to tackling the barriers that exist to introducing Recovery Package interventions, such as commissioning, staff training and digital systems. Addressing issues around the quality of Cancer Care Reviews is also important. As with Stratified Follow Up, ongoing sharing of best practice, and learning about the barriers and enablers, is vital to ensure full spread of the Recovery Package by 2020.

1.3 Overall

Overall, there is strong indication that in early 2017, most trusts had experience (in at least one MDT) of Stratified Follow Up pathways and Recovery Package

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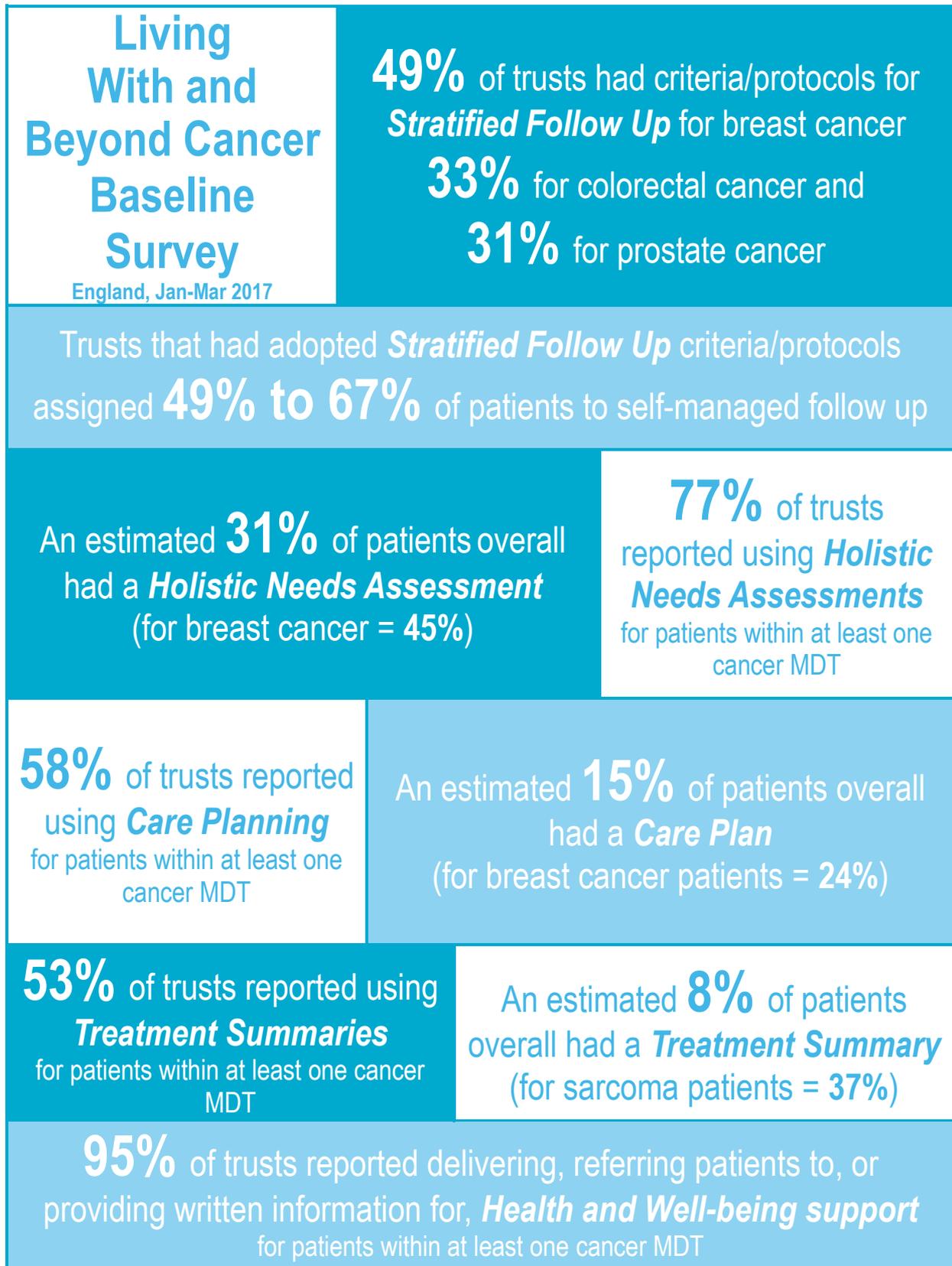
interventions. Where implemented, trusts reported that these transformational changes were producing the anticipated results, for example, freeing up outpatient capacity and improving patient experience and well-being.

Progress against the baseline figures in this report will have already been made nationally in the last 12 months, helped by Cancer Alliance transformation funding. It is therefore expected that 2018/19 will see further significant improvement, leading to achievement of national strategy commitments for Stratified Follow Up and Recovery Package by 2020/21. NHS England will work with Cancer Alliances and other stakeholders to support and accelerate progress.

While there were difficulties with data collection, this is not surprising as the survey covered a time period prior to any standardisation of approach. NHS England is using the findings to set standards and methodology for routine data collection and analysis which will then be made available at an Alliance level via CADEAS. The first collection of standardised data is being planned to cover Quarter 3 2018/19. This will be part of a proposed Outcomes Framework which will also assess the planned outcomes and impact of Stratified Follow Up pathways and Recovery Package interventions, including:

- Improved survival
- Improved symptoms and quality of life
- Improved patient experience
- Improved management of comorbidities
- Reduced demand for cancer team, urgent/emergency and/or GP care
- Reduction in cancer waiting times
- System efficiencies.

Figure 1. Summary results of Stratified Follow Up Pathway and Recovery Package surveys of NHS trusts, January to March 2017



2 Introduction

Personalised follow up and support to help people live with and beyond cancer is one of the cornerstones in creating world class cancer services. The NHS Cancer Programme is delivering a five-year plan to improve NHS cancer services. We are already making rapid progress – but know there is more to do. Overall, we are on track to make long term changes that will put NHS cancer services up with the best in the world.

Cancer Alliances are leading ambitious transformation programmes to deliver Stratified Follow Up pathways and Recovery Package¹ interventions for patients across England. In some areas, patients have been benefiting from this personalised approach to care and support for many years, whilst in others, roll out is still in its early stages. It is extremely important that benefits for patients and equity of access are achieved, and in order to do so, a better understanding is needed of where variation exists and how future progress should be measured and monitored.

To support this, NHS England commissioned research to establish a baseline of data and to understand:

- what, and how, Stratified Follow Up pathway and Recovery Package activity data is currently collected locally and nationally;
- how best to implement regular reporting and targets for improvement;
- how activity levels differ by Alliance, trust, intervention and cancer type; and
- the barriers and enablers to implementation.

Two surveys covering the time period January to March 2017 were designed in consultation with Cancer Alliances and other key stakeholders – one for Stratified Follow Up pathways and one for Recovery Package interventions.

The results at Alliance level were shared with Alliances in March 2018 and were designed to support them:

- in establishing a baseline (from January – March 2017) with the trusts in their areas for how they are delivering Stratified Follow Up pathways and Recovery Package interventions,
- in having consistent measurement of the interventions across the Alliance area – using the same metrics across all trusts and
- in being able to see where there might be issues or areas of concern so Alliances know where to focus additional support, perhaps with trusts or MDTs where Stratified Follow Up pathways or Recovery Package activity has not yet started or are just now being brought into the Alliance-wide activity on Living With and Beyond Cancer.

¹ Recovery Package interventions for the purposes of this report are: Holistic Needs Assessment, Care Planning, Treatment Summaries, Health and Well-being support and Cancer Care Reviews.

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This national level report is designed to provide information that will help NHS England:

- to define the consistent metrics for measurement of Stratified Follow Up pathways and Recovery Package interventions nationally - to enable regular reporting that can be played back to Alliances through the CADEAS reporting;
- to understand the barriers and enablers to data collection and roll out of Stratified Follow Up pathways and Recovery Package interventions so that these can be unblocked at a national level and Alliance level.

It is important to be aware that although we have tried to ensure the data is as accurate as possible, there is some under-reporting on Stratified Follow Up pathway and Recovery Package activity because some trusts reported they were not able to collect the full survey data, or left survey questions blank.

In addition, Cancer Care Review data is not provided in this report, as it was not possible to collect data on the survey questions comprehensively enough at this point. Official Cancer Care Review activity data for 2016/17 as part of the General Practice Quality and Outcomes Framework (QOF) is available [from NHS Digital](#).

This was the first-ever national collection of Stratified Follow Up pathway and Recovery Package intervention activity data. We are grateful to all the Cancer Alliances for providing support with the development, distribution and collation of the surveys and to Macmillan Cancer Support for overall support.

3 Methodology

Two surveys were designed in consultation with Cancer Alliances and other key stakeholders:

- Stratified Follow Up pathways - covering breast, prostate and colorectal cancer only,
- Recovery Package interventions, i.e. HNAs, Care Planning, Treatment Summaries and Health and Well-being support, covering MDTs for breast, urology, upper gastrointestinal (GI), lower GI, brain and central nervous system (CNS), head and neck, sarcoma, skin, haematology, gynaecology and lung.

Survey questions are provided in Appendix 2.

The number of trusts that offer cancer treatment were calculated using datasets from NHS England on Provider-based Cancer Waiting Times and from the CancerStats website on Cancer Outcomes and Services Dataset (COSD).

It was agreed to survey the time period January to March 2017 as, at the time of issuing the questionnaires, this would be the period that would have the most complete and accurate information available. Frontline Consultants were commissioned to administer the surveys, collect data and analyse the results. Cancer Alliances acted as the intermediaries to ensure that as many trusts as possible completed the surveys. Due to difficulties in data collection, the deadline for submitting survey returns was extended to December 2017. This national report is prepared from the data tables provided by Frontline Consultants.

To provide a proxy of the 'population' of cancer patients to whom the Stratified Follow Up pathway and Recovery Package activities should apply in the quarter, it was decided to use Cancer Waiting Times data on patients receiving first definitive treatment within 31 days of diagnosis. However, some trusts provided Decision to Treat figures. Additional difficulties occurred in providing data due to Trust mergers, lack of IT systems at that time, lack of staff resource to collect data, and uncertainty whether tertiary cancer centres should be providing data on activity that may be the responsibility of the referring secondary care centre. Questions emerged on whether the count of HNA activity could exceed the 'population' number, as individuals may receive several HNAs in a quarter. Equally, more people could be placed on Stratified Follow Up pathways than the 'population' number, potentially due to trusts having a 'big bang' move of previously treated patients onto Stratified Follow Up pathway. Neither of these issues were corrected for in the results.

A third survey, on Cancer Care Reviews, was disseminated, However, results are not provided in this report, as it was not possible to collect data on the survey questions comprehensively enough at this point. Official Cancer Care Review activity data for 2016/17 as part of the General Practice Quality and Outcomes Framework (QOF) is available from [NHS Digital](#) (see section 4.3.8).

4 Results

4.1 Data Collection

60% of trusts provided responses to the Stratified Follow Up pathway survey, and 69% to the Recovery Package survey (Table 1). The survey responses included both quantitative data, and a wealth of qualitative data on different aspects on Stratified Follow Up pathway and Recovery Package implementation and the challenges of data collection and use.

Table 1. Survey response rates from trusts that offer cancer treatment

Region	Cancer Alliance	Trusts in Alliance Area	No. of Trusts who responded	
			Stratified Follow-Up Survey	Recovery Package Survey
North	North East and Cumbria	9	2	3
	Lancashire and South Cumbria	4	4	4
	West Yorkshire	6	4	4
	Humber, Coast and Vale	3	2	2
	National Cancer Vanguard: Greater Manchester	9	4	4
	Cheshire and Merseyside	15	5	8
	South Yorkshire, Bassetlaw, North Derbyshire and Hardwick	6	4	4
Midlands & East	West Midlands	19	7	9
	East Midlands	7	7	7
	East of England	19	17	19
South	Peninsula	5	2	2
	Somerset, Wiltshire, Avon and Gloucestershire (SWAG)	8	7	7
	Thames Valley	4	3	3
	Wessex	7	6	7
	Surrey and Sussex	9	2	2
	Kent & Medway	4	4	4
London	National Cancer Vanguard: North Central and North East London	10	5	7
	National Cancer Vanguard: North West and South West London	10	7	10
	South East London	3	3	3
	Total	157	95	109
	As a % of total		60%	69%

Note: Some trusts sent survey returns which only included population data. These trusts are not included in the table above.

4.2 Stratified Follow Up Pathways

Stratified Follow Up pathways embody a whole person, whole pathway, personalised approach to care. The clinical team and patient make a decision about the best form of follow up. Care is tailored according to the severity and complexity of a person's individual and clinical needs, including their knowledge of the disease, their treatment and their ability to self-manage. In general, those at low risk of recurrence and late effects should be supported to self-manage with remote monitoring for disease recurrence; those at medium risk may receive planned coordinated care; those at high risk should receive care from specialist services. Patients can move between the different levels of care as their needs change and are given a key contact point for rapid re-entry if required.

4.2.1 Stratified Follow Up Pathway Results

Of the trusts who responded to the Stratified Follow Up pathway survey, 49% had criteria/protocols in place in January – March 2017 for assigning breast cancer patients to supported self-managed follow up, 33% for colorectal and 31% for prostate cancer (Table 2). A third of trusts reported having remote monitoring systems.

Table 2. Proportion of trusts reporting having Stratified Follow Up criteria/protocols for, and key features within, their breast, colorectal and/or prostate cancer supported self-management follow up pathways (Jan-Mar 2017)

For self-managed follow up pathways for:	Breast Cancer	Colorectal Cancer	Prostate Cancer
	As a % of the 95 trusts responding to the Recovery Package survey		
Criteria/protocols in place for assigning patients to a Supported Self-managed Follow-Up Pathway (see Note)	49%	33%	31%
Key features	Breast Cancer	Colorectal Cancer	Prostate Cancer
Contact details/helpline for the specialist team	53%	35%	32%
Rapid re-access to the specialist team as required	52%	31%	27%
Implementation/continuation of all Recovery Package interventions	37%	20%	17%
Co-ordination between secondary and primary care	35%	16%	18%
A remote monitoring system to manage on-going surveillance tests	34%	20%	21%

Table 2 Note: 15 trusts reported criteria/protocols for all 3 cancers, and 16 reported criteria/protocols in 2 out of the 3 cancers. 13 trusts also reported having protocols for other cancer types.

Overall, 3,363 patients were reported as being assigned to self-managed follow up, but this will be a significant underestimate due to difficulties with data collection. When taken as a proportion, trusts that had Stratified Follow Up pathway criteria/protocols were assigning between 49% and 67% of patients to self-managed follow up (Table 3).

It should be noted that a small number of trusts had more patients assigned to self-managed follow up than there were patients receiving definitive treatment in the quarter January – March 2017 (data not shown). This probably reflected where trusts had recently introduced a Stratified Follow Up pathway approach, and had assigned previously treated, as well as newly treated, patients to self-managed follow up, thus showing as a ‘bulge’ in the figures for that quarter. All data on Stratified Follow Up pathways should be interpreted with caution unless it is known if and when trusts have been assigning patients in this way.

Table 3. Estimated number of patients reported as being assigned to self-managed follow up for Breast, Colorectal and/or Prostate Cancer (Jan-Mar 2017)

	Breast Cancer	Colorectal Cancer	Prostate Cancer
No. of patients reported as being assigned to self-managed follow up (Note 1)	2412	274	677
Proportion of patients assigned to self-managed follow up (note 2)	67%	49%	53%

Note 1: Patient numbers were only reported by about two-thirds of the trusts who stated they had pathway protocols/criteria, therefore capture of this data was incomplete and the figures will be an underestimate.

Note 2: Patients assigned to self-managed follow up as a % of the number reported as receiving first definitive treatment within 31 days of diagnosis, only in the trusts who reported both having criteria/protocols and reported patient numbers assigned to self-managed follow up.

Trusts reported a wide range of indicative targets for self-managed follow up (table 4). The most common target reported for breast cancer was in the range 70 to 79%, while colorectal and prostate were both in the range 40 to 49%. These figures are broadly in line with the previously recommended figures for self-managed follow up, namely 75% for breast, 45% for colorectal and 30% for prostate².

² [NHS Improvement \(2013\) Stratified Pathways of Care: How to Guide](#)

Table 4. Trusts (n = 23) reporting indicative targets for the proportion of patients suitable for self-managed follow up

Indicative targets for the proportion of patients suitable for self-managed follow up:	Breast	Colorectal	Prostate
	No. of trusts		
20 - 29%	1	0	1
30 – 39%	0	0	2
40 – 49%	0	7	6
50 – 59%	1	2	2
60 – 69%	0	1	1
70 – 79%	9	0	0
80 – 89%	6	0	0
90 – 100%	2	1	0

4.2.2 Stratified Follow Up Pathway Implementation

Many trusts provided written feedback about what has worked well with Stratified Follow Up pathway implementation and data collection as well as the challenges. Examples are:

- A trust using data to demonstrate outcomes said: *“Currently showing decline in activity in traditional clinics as predicted and positive patient experience. Quantitative evidence in particular has aided engagement with some clinicians in other sites less engaged with the work.”*
- An Alliance has observed wider benefits: *“From their own experience of Living with and Beyond Cancer, patients wanting to be more involved in promoting the Public Health Message of cancer prevention for their type of cancer is emerging strongly in a number of our support groups and has been picked up by [...] the CCGs.”*
- Several trusts commented that, while the work to introduce Stratified Follow Up pathways has been hard work, there were definite long term benefits. For example: *“Clear criteria and simple pathway has enabled the work to be easily replicated and applied elsewhere, three other hospitals have taken our work to look at applying locally for their needs”; “Project leads and admin / support workers are required for this transition period for this new way of working to be implemented in a timely and efficient manner”; and, “Initial scepticism of team which has now become positive with note made of excellent co-ordination and benefits of Health and Wellbeing Events”.*
- A few trusts observed the switch-over to Stratified Follow Up pathway can create new pinch points, for example: *“Have great system in place but lack of clinical nurse specialist time to do Exit Interviews/run service has meant that*

not all patients that could have open access are being put into this”; and, “Support workers’ capacity to attend clinics required due to success of programme”.

- Financial barriers were also a theme, for example, some trusts’ comments included: *“Post ending once project comes to an end”; “Loss of revenue”; and, “Not commissioned so not funding”.*

4.3 Recovery Package

4.3.1 Holistic Needs Assessment (HNA) and Care Planning

This takes place for all cancer patients around the time of diagnosis, end of treatment, and whenever a patient’s needs change or they request it. It creates a shared understanding between a patient and their team, identifying a patient’s physical, practical, emotional, lifestyle and social needs to ensure these are met in a timely and appropriate way.

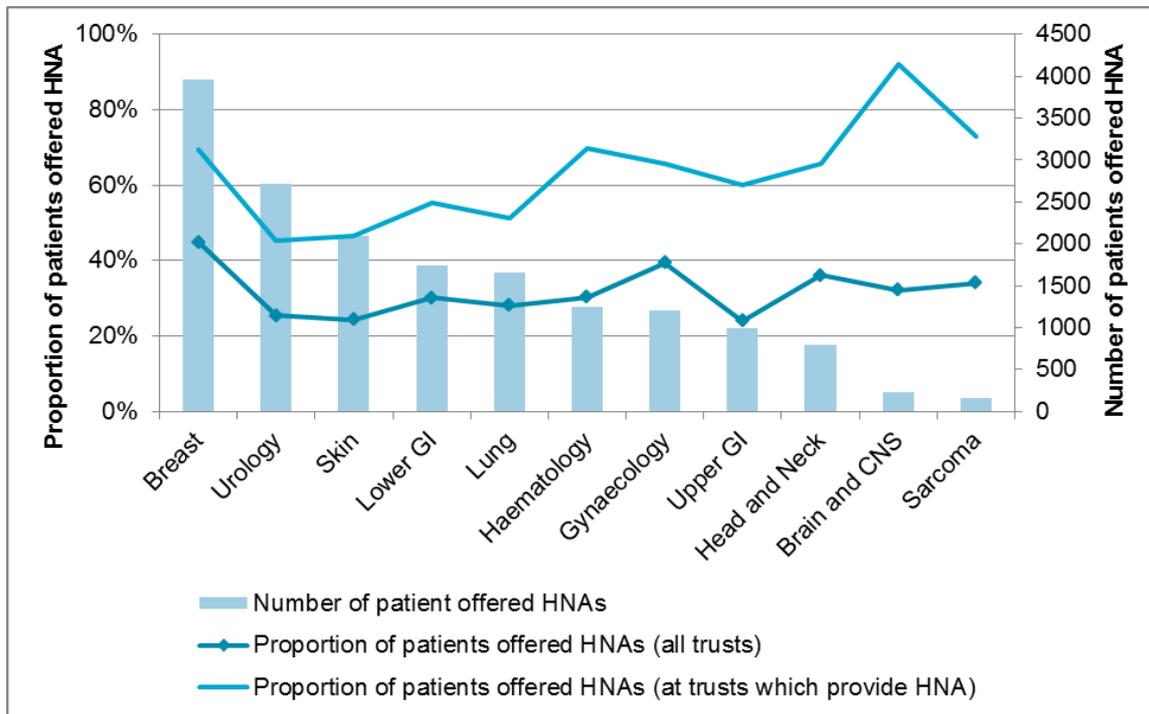
4.3.2 Holistic Needs Assessment (HNA) and Care Planning Results

Level of Holistic Needs Assessment and Care Planning

Out of 109 trusts who completed the Recovery Package survey, 84 (77%) reported using HNAs within at least one MDT for January – March 2017 (for HNAs held at any time in the patient’s cancer journey). This indicates that by the time of writing (March 2018), a high proportion of trusts are likely to have introduced the use of HNAs, thus forming a solid base from which to spread their use to all other MDTs within each trust.

In total, 16,805 HNAs were reported for January – March 2017. If it is assumed that in that three-month period, people would not usually have had more than one HNA each, this figure represents 31% of the number of people receiving first definitive treatment within 31 days of diagnosis. When split by cancer type, MDTs were reporting HNAs for between 24% for Skin and Upper GI patients and 45% for Breast patients at all trusts (Figure 2). When taken as a proportion of only trusts reporting HNAs, the proportions range from 45% of urology patients to 92% of brain and CNS patients. However, these are still likely to be underestimates due to difficulties in collecting this data.

Figure 2. Estimated number and proportion of cancer patients having a Holistic Needs Assessment (HNA), by cancer type (Jan-Mar 2017)



An HNA should lead to a discussion and agreement with the healthcare professional to create a care and support plan for the patient.

Out of 109 trusts who completed the Recovery Package survey, 63 (58%) reported preparing Care Plans within at least one MDT for January – March 2017. A total of 8,133 Care Plans were reported, representing an estimated 15% of all patients receiving first definitive treatment within 31 days of diagnosis. In comparison, in the national Cancer Patient Experience Survey (CPES) for 2016, 33% of patients reported that they were given a Care Plan³. It is likely that both CPES and the Recovery Package survey figures are underestimates of the actual prevalence of Care Planning, but they still indicate this is an area that needs focus for improvement.

At trusts reporting use of HNAs, the proportion of patients who received a Care Plan was between 34% for sarcoma and 59% for Upper GI cancer (Figure 3).

It is accepted that the ‘conversion rate’ of HNAs to Care Plans is always less than 100% (the Macmillan eHNA project reported a conversion rate of 72% in 2015⁴ but is

³ CPES definition: “A care plan is a document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional to help meet those goals”.

⁴ Ipsos MORI for Macmillan Cancer Support (2015). Evaluation of the electronic Holistic Needs Assessment. “Where care plans are not created, the primary reason is lack of time. This may mean healthcare professionals prioritise writing care plans for people known to have complex needs. Indeed, some healthcare professionals say care plans are not created if individuals have low-level, or no, concerns.”

known to be higher than this in 2018). The number of Care Plans will therefore be lower than the number of HNAs. The proportion of HNAs reported as being converted to Care Plans is shown in Figure 4.

Figure 3. Estimated number and proportion of patients receiving a Care Plan, by cancer type (Jan-Mar 2017)

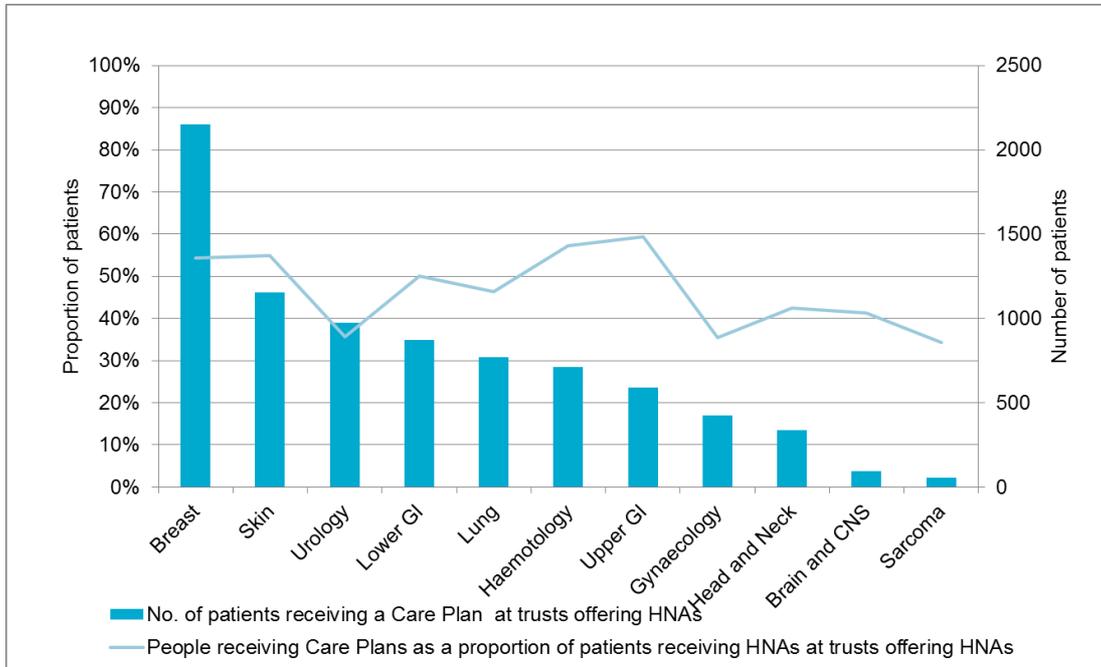
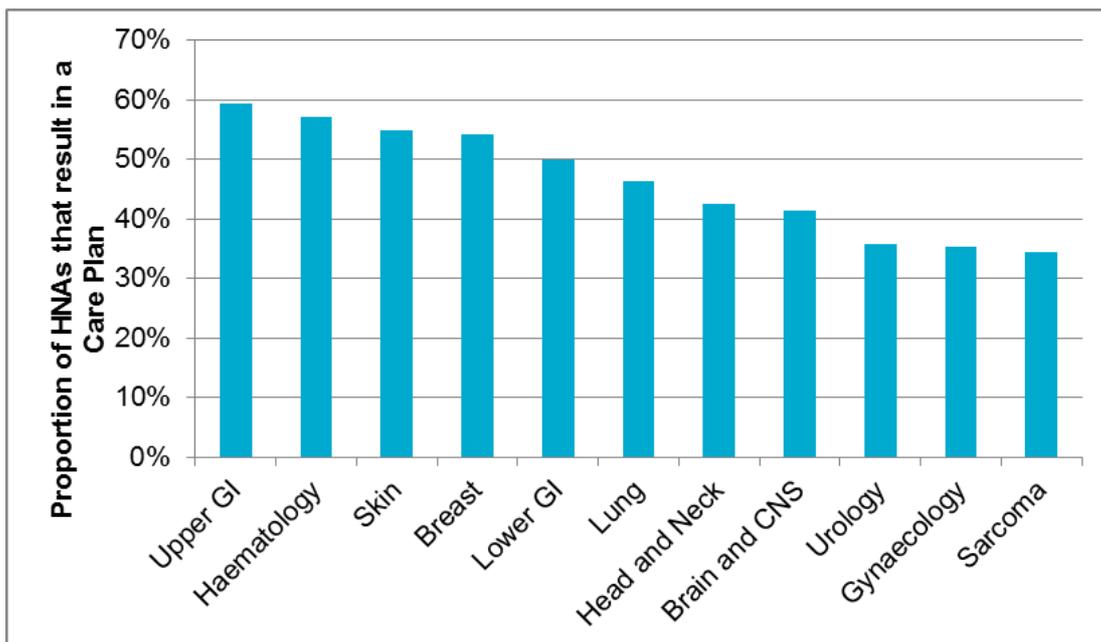


Figure 4. Estimated proportion of Holistic Needs Assessments (HNAs) that result in Care Plans, by cancer type, Jan – March 2017



Timing and Methods of Holistic Needs Assessment

Trusts were asked when HNAs and Care Planning are most likely to be undertaken. The responses show that in January to March 2017, trusts reported that MDTs most frequently carry these out at (or shortly after) diagnosis, with significant numbers also done at end of final treatment, and when the patient asks for it (Table 5). Some trusts also specified other time points used by some MDTs, such as at diagnosis of recurrence, or transfer to palliative care.

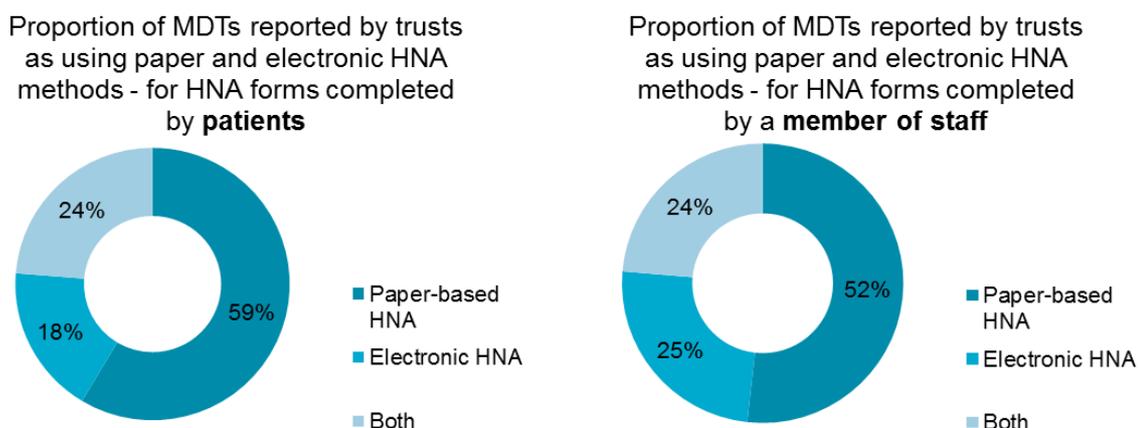
Table 5. MDTs reporting the time points when Holistic Needs Assessment and Care Planning are likely to occur, Jan – March 2017.

Time points for Holistic Needs Assessment and Care Planning	Estimated total no. of MDTs (as reported by trusts)
At, or shortly after, diagnosis	See note
At the end of final treatment	345
At the end of each cycle of treatment	98
When the patient asks	307

Note 1: 'At, or shortly after, diagnosis' was not a survey answer option but most trusts provided written information about MDTs who carry out HNAs around this time point. From this information, it strongly suggests that they were done at a similar frequency at this time point as at the end of final treatment.

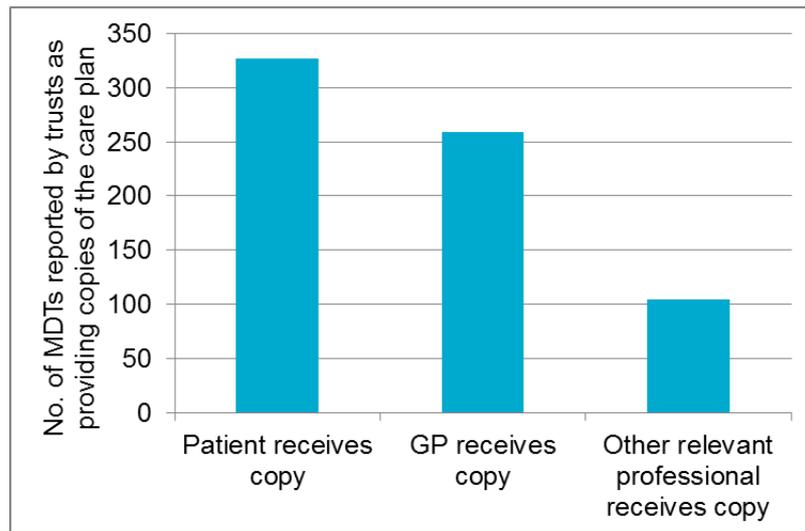
The method of capturing the results of HNAs varies considerably by MDT and by trust (Figure 5a). Overall, paper HNA forms were being used more often than electronic devices (such as the Macmillan eHNA on tablet, computer or mobile phone). It would be expected that over time there will be a much greater shift to electronic HNA tools. However, if they are not available, then paper HNAs still remain a highly valuable tool to inform the conversation about patient concerns and holistic needs.

Figure 5a. Methods of recording Holistic Needs Assessment, by cancer type, Jan-Mar 2017



Staff tended to complete more HNA forms than patients. When asked who the HNA and Care Plan was shared with, trusts most often reported that the patient receives a copy, closely followed by the patient's GP, and occasionally other healthcare professionals (Figure 5b).

Figure 5b. Who receives a copy of the Care Plan, by cancer type, Jan-Mar 2017

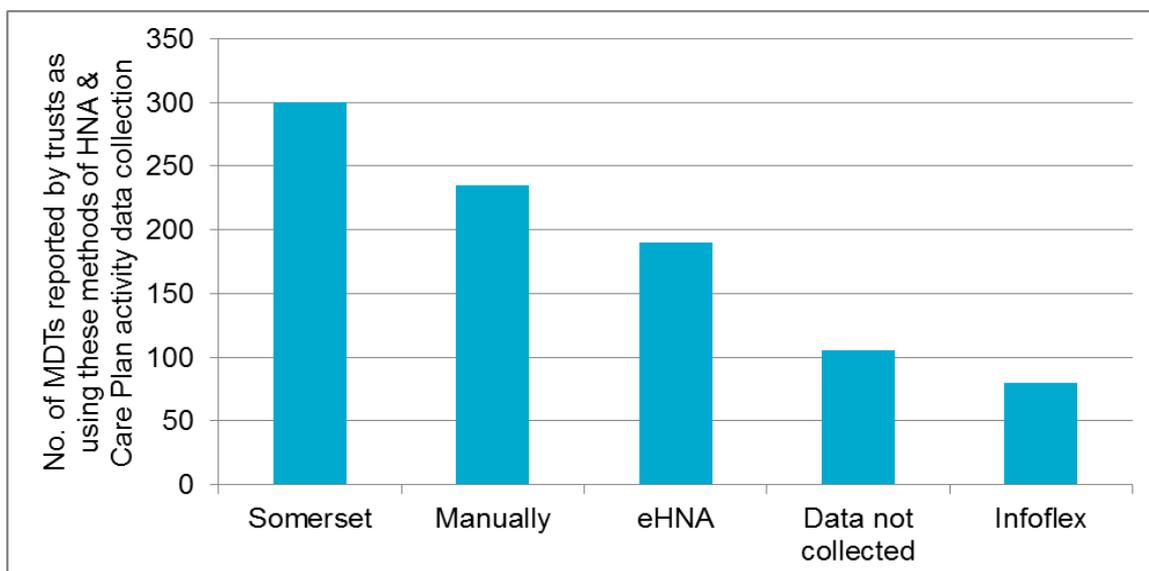


Data collection for Holistic Needs Assessment and Care Planning

Most trusts were using IT to collect data, but around a quarter of trusts were collecting it manually (Figure 6). Trusts use two main systems for collecting cancer data (for example, to support monitoring of cancer waiting times): Inflex and Somerset. Both have developed features to allow data collection for HNAs, Care Planning, Treatment Summaries and Health and Well-being events, but in early 2017 these would not have been universally available and in use. The Macmillan eHNA system collects data on HNAs and Care Plans only. The survey results indicate that only a small proportion of MDTs were not collecting any HNA/Care Plan data at all.

Overall, while there are acknowledged difficulties around data collection, it would appear that most trusts are in a good position to adapt when standardised metrics and definitions are agreed in 2018.

Figure 6. Data collection for HNA and Care Planning, by cancer type, Jan-Mar 2017



4.3.3 Treatment Summaries

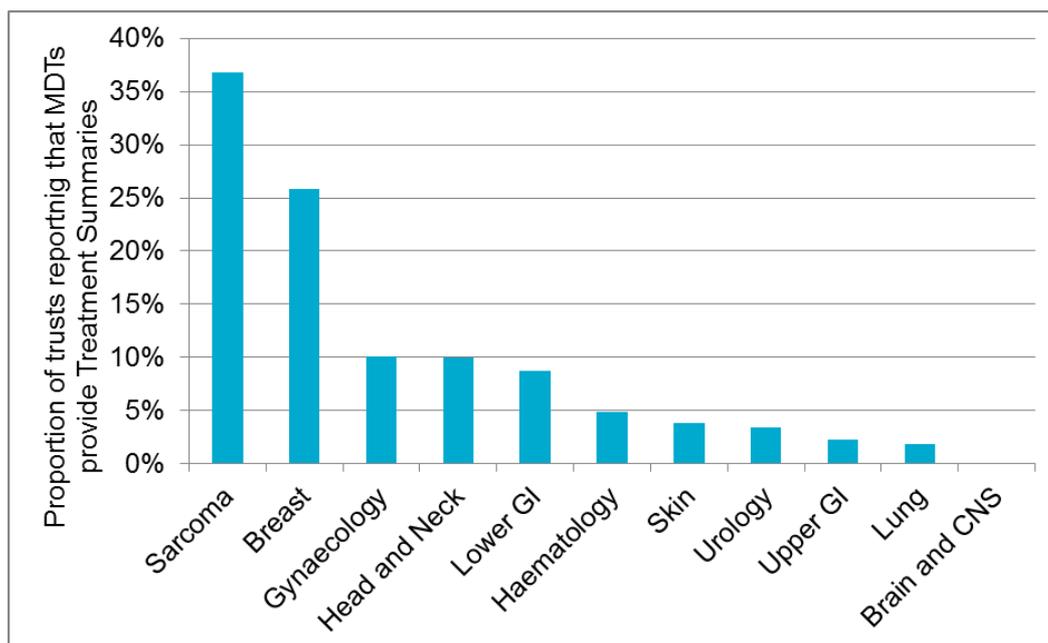
Secondary care providers produce Treatment Summaries at the end of each treatment stage and may be used at other points, such as referral to palliative care. A copy is sent to the GP and patient. It supports improved communication so that primary care knows how to support the patient, for example, with treatment consequences. It helps improve the patient's understanding of their condition, their treatment and what they can do to help themselves.

4.3.4 Treatment Summaries Results

Of the 109 trusts who responded to the Recovery Package survey, 58 (53%) reported using Treatment Summaries in at least one cancer MDT.

In total, 4,580 Treatment Summaries were reported for January – March 2017. When split by cancer type, MDTs were preparing them for 37% of sarcoma patients but the average across all cancers was only 8% (Figure 7). As for other aspects of the Recovery Package, these figures are likely to be significant underestimates due to difficulties in collecting this data.

Figure 7. Estimated provision of Treatment Summaries, by cancer type, Jan-Mar 2017



Recommendations have been made by Macmillan Cancer Support for the information that should be included in Treatment Summaries⁵. Trusts reported for January – March 2017 that the most commonly provided information was details of cancer treatment (Table 6). Other key information was provided with less frequency, in particular about signs and symptoms of recurrence and consequences of treatment.

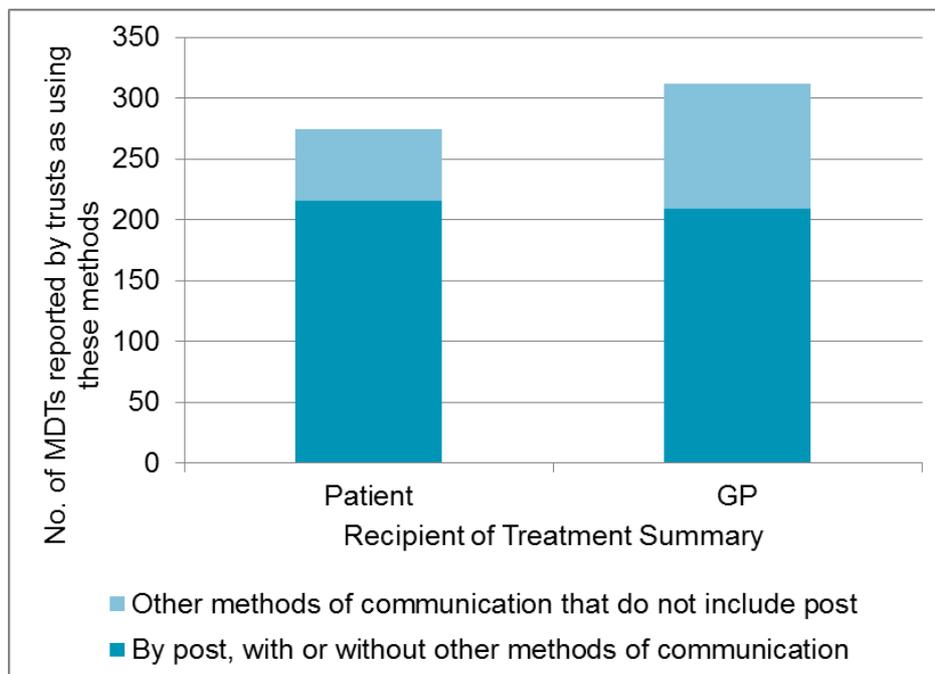
⁵ [Macmillan Cancer Support \(2016\) Treatment Summary How To Guide](#)

Table 6. Inclusion of information items in Treatment Summaries, Jan-Mar 2017

Key Information in a Treatment Summary	Estimated total no. of MDTs (as reported by trusts)
Details of cancer treatment	398
Details of who to contact for any questions or concerns	338
Actions that need to be taken by primary care	319
Details of possible side effects	304
Signs and symptoms of recurrence	282
Details of possible consequences of treatment	262
Advice on how to manage consequences of treatment	243

The vast majority of treatment summaries were created by a health professional (rather than a support worker). They were mainly shared by post or via a conversation with patients, and by post or electronically with GPs (Figure 8). This data should be interpreted as indicative only, but it is likely that the preferred method of sharing information with patients and GPs was by post, giving scope for increasing secure electronic communication.

Figure 8. Method of communicating Treatment Summaries to patients and GPs, Jan-Mar 2017.



4.3.5 Health and Well-being Support

Health and Well-being support (for example, an event) provides an opportunity to inform and educate patients about the clinical and holistic aspects and ongoing management of their health and is offered to all patients – courses and events usually occur at the end of treatment but education can happen at any time. It may include: advice on healthy living and physical activity; targeted information on likely side-effects of treatment and symptom management; potential markers of recurrence and what to do in these circumstances; information on complementary therapies; and, work support/vocational rehabilitation.

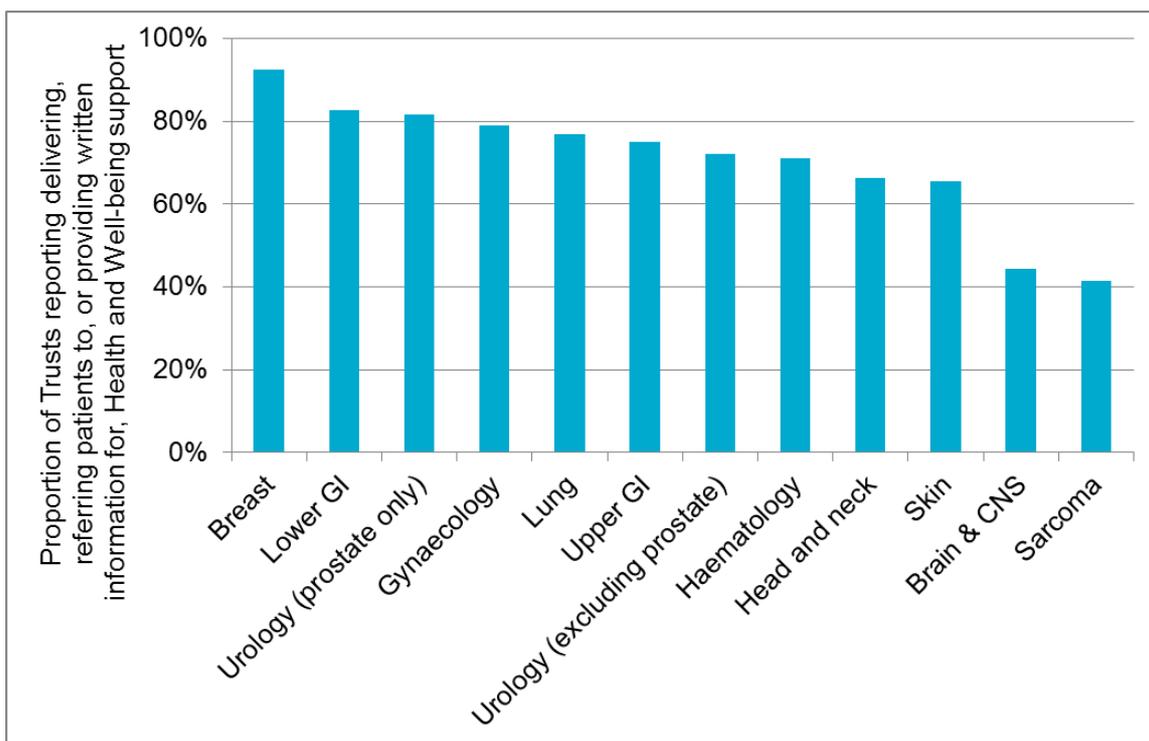
4.3.6 Health and Well-being Support Results

Out of 109 trusts that completed the Recovery Package survey, 96 (95%) reported delivering, referring patients to, or providing written information for, Health and Well-being support for patients within at least one MDT for January to March 2017. Most trusts reported that Health and Well-being support events were open to all patients, but some had cancer site-specific events, most commonly for breast cancer.

This indicates that by the time of writing (March 2018), all trusts are likely to have introduced the use of Health and Well-being support, thus forming a solid base from which to spread their use to all other MDTs within each trust.

When split by cancer type, MDTs were offering Health and Well-being support for between 41% for sarcoma patients and 92% for breast cancer patients (Figure 9).

Figure 9. Provision of Health and Well-being Support (delivering, referring patients to, or providing written information for, health and well-being) by cancer type, Jan-Mar 2017



When asked what format the Health and Well-being support activity took, the vast majority of trusts reported offering a combination of written patient information and in-house Health and Well-being events/courses, and a high proportion also referred or signposted patients to a very wide variety of events and courses held by other organisations, including:

- Macmillan Cancer Support – support and information centres, well-being courses (such as HOPE)
- Breast Cancer Care – Moving Forward course
- Maggie’s Centres
- Breast Cancer Haven
- Penny Brohn – Living Well course
- Trekstock for young adults
- Lymphoma Association – Living Well With and Beyond Lymphoma
- Look Good Feel Better
- Local hospices, cancer charities and patient support groups
- Courses, sessions and sources of advice and support not specifically for cancer patients, such as Citizen’s Advice Bureaus, Age UK, YMCA and local authority provision for physical activity, well-being and health promotion.

Not all trusts covered the same range of topics in either in-house or external courses or sessions (Table 7). Physical activity, finances, diet and nutrition, psychological well-being and fatigue were covered by most, but other important topics such as symptoms of recurrence, work and consequences of treatment would appear to be covered less frequently⁶.

Table 7. Topics covered in Health and Well-being courses/sessions (in-house or external), Jan-Mar 2017

Topic	Estimated total no. of MDTs (as reported by trusts)
Physical activity	723
Finances	679
Diet and nutrition	678
Psychological well-being	678
Coping with fatigue	672
Anxiety and depression	610
Work	562
Consequences of treatment	525
Symptoms of recurrence	477
Social care support	377
Follow up in the community/GP	357

⁶ [Macmillan Cancer Support has produced a How To guide on Health and Well-being events](#)

Other topics covered in events led by non-NHS organisations included: lymphoedema support, rehabilitation, breathlessness, stoma support, buddying/befriending, vocational rehabilitation, fatigue management, physical activities (walking, swimming, gardening), psychological support, resilience, creative activities (singing, dance, writing), relaxation, complementary therapies, side effects of treatment and mindfulness.

It was not possible to obtain comprehensive data on the number of people being invited to Health and Well-being events and courses, as information on non-NHS events was not available. Data indicates that 10 to 20% of people attend in-house events, but it is not clear what proportion are invited but decline to attend.

4.3.7 Recovery Package Implementation

Many trusts provided written feedback about what has worked well with Recovery Package implementation and data collection as well as the challenges.

Examples are:

- A trust who has developed electronic sharing of Treatment Summaries :
“Letter templates developed and uploaded onto the electronic patient record and shared electronically with GPs where possible”.
- Trusts are using Recovery Package activity and audit data to support service improvements, including :
 - *“Gap analysis of HNA data has allowed us to see where we are not doing HNA that we would like to and focus efforts. We have also funded additional staff where gaps have been identified. eHNA data is now being used to inform workshops at the Macmillan Support and Information Service”*
 - *“Audit [...] highlighted that patients who do not attend a results clinic do not receive a [Treatment] Summary. A departmental decision was then taken to replace discharge letters with Treatment Summaries”*
 - *“The drop out figures were instrumental in changing from a four week [health and wellbeing] course to a 1 day course”*
 - *“Increase in referrals to clinical psychology for all tumour sites as awareness increases, showing patient need”.*
- Challenges were similar to those for Stratified Follow Up pathways, for example:
 - Some trusts commented on the difficulty of staff engagement: *“Staff not seeing the value and importance of the HNA”* and *“Difficulties getting*

clinicians to change from traditional style of letter [to treatment summary]”.

- A lack of resources was also problematic, with some trusts’ comments including; “*Sessions running on ‘good will’*”; “*Lack of substantive paid roles to deliver*”; and, “*Limited venue availability*”.

4.3.8 Cancer Care Reviews

As stated earlier, results from the survey of Cancer Care Reviews (CCR) are not available. The survey questions are shown in Appendix 2.

QoF results for 2016/17 for the CAN003 CCR indicator⁷ show that, once agreed exceptions were excluded (25.31% of all patients), 94.16% of eligible patients with cancer, diagnosed within the preceding 15 months, have a patient review recorded as occurring within 6 months of the date of diagnosis.

A session was held in late 2017 with Macmillan GP Advisors to explore issues around data collection for CCRs. This highlighted the need for future work on measuring CCR activity to consider:

- Route for requesting the data (via CCG or Cancer Alliance)
- Explaining the rationale for NHS England data collection
- Data should be useful locally to support CCR improvement, and other aspects of LWBC in primary care
- Manageable number of data items for GPs to provide
- Focus on quality rather than quantity of CCRs
- Disincentive to provide data that might appear to give a different response to QoF CAN003 requirements
- Analysing use of CCR templates on GP IT systems
- In-depth audit of a sample of practices.

⁷ The percentage of patients with cancer, diagnosed within the preceding 15 months, who have a patient review [in primary care] recorded as occurring within 6 months of the date of diagnosis.

5 Next Steps

5.1 Data collection

NHS England will work in 2018/19 with Cancer Alliances and other key stakeholders to introduce consistent data collection to monitor access to Stratified Follow Up pathways and Recovery Package interventions. This will involve developing agreed data definitions and metrics for each intervention, establishing an outcomes framework and support tools for Alliances and CCGs, and ensuring that the main IT providers make updates in line with national policy requirements, so that organisations can record consistent data. It is planned to first collect the standardised data for Quarter 3 2018/19.

5.2 Stratified Follow Up

NHS England will work in 2018/19 with Cancer Alliances and other key stakeholders to ensure that information and support is available to tackle the barriers that exist to introducing Stratified Follow Up pathway for breast, colorectal and prostate cancer patients. All stakeholders should continue to share learning about the barriers and enablers (for example, from the Alliance-level baseline reports), as well as understanding the situation with implementation with rarer cancers, as this will help to accelerate progress. Alliances should identify which trusts/MDTs would need targeted support during 2018/19, prioritising work to ensure that the national target is met for 100% of trusts to have breast cancer Stratified Follow Up pathway protocols and remote monitoring systems by March 2019.

5.3 Recovery Package

NHS England will work in 2018/19 with Cancer Alliances and other key stakeholders to ensure that information and support is available to tackle the barriers that exist to implementing Recovery Package interventions. All stakeholders should continue to share learning about the barriers and enablers (for example, from the Alliance-level baseline reports), as this will help to accelerate progress. Alliances should identify which trusts/MDTs would need targeted support during 2018/19. Nationally, there should be a focus on making more progress on Treatment Summaries and Care Planning.

6 Appendix 1: Acknowledgements

Thank you to all contributors, including:

All Cancer Alliance and trust staff who helped with the survey and data collection.

Macmillan Cancer Support.

Frontline Consultants.

NHS England Cancer Programme team.

7 Appendix 2: Survey wording and questions

Note: where the wording of questions below refers to data being collected for 'each tumour type', it was requested for Breast; Urology (prostate only); Urology (excluding prostate); Lower GI; Upper GI (including Hepatobiliary and Pancreatic); Gynaecology; Haematology; Head and neck; Brain and CNS; Lung; Sarcoma; Skin; Other (please specify cancer type and number).

RECOVERY PACKAGE – PROVIDER SURVEY

This survey will provide a baseline of Recovery Package activity. It will also support:

- the identification of options for improving consistency and robustness of local data collection on activity to enable national/local monitoring and reporting
- areas for improvement at local and national levels
- the capture of examples of how the various elements of the Recovery Package have been implemented and how challenges have been overcome that can be shared with others

We appreciate that not all the information may be available, a key part of this exercise is to understand this so that improvement can be supported. Where data is not available, we would ask you to complete the field with the text 'not available'.

CANCER ALLIANCES SHOULD PLEASE RETURN – *one Recovery Package Survey for each provider trust.*
Collated surveys should be sent to [Frontline Consultants] by 20th October 2017

We would like to thank you for your support in helping to create the baseline. Should you have any questions on the survey/its operation or require any support please contact: [Frontline Consultants]

1. Name of trust.
2. Name/title of individual(s) completing the survey.
3. Number of patients receiving first definitive treatment within 31 days of diagnosis* in 2016/17 Quarter 4 (January 1st 2017 to March 31st 2017) for each tumour type.

*This is a proxy only as it is recognised that patients will not always receive Recovery Package interventions at the end of treatment within the same quarter as decision to treat.

HOLISTIC NEEDS ASSESSMENT AND CARE PLAN

1. Number of patients who received a Holistic Needs Assessment within Q4 2016/17 for each tumour type.
2. Number of patients for whom a care plan was produced in Q4 2016/17 for each tumour type.
3. When is the Holistic Needs Assessment and care planning most likely to be undertaken?

Tick boxes were provided broken down by tumour site and tick each option relevant out of the following:

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- At the end of each cycle of treatment
- At the end of final treatment
- When the patient asks for it
- Other – please specify with reference to tumour site(s)

1. What does the Holistic Needs Assessment and Care Planning process involve?

Tick boxes broken down by tumour site and tick each option relevant out of the following:

- Patient completes a paper concerns checklist on their own before an appointment
- Patient completes an electronic checklist on their own before an appointment
- Member of staff completes a paper checklist during consultation with the patient
- Member of staff completes an electronic checklist during consultation
- A real-time conversation is undertaken with the patient by:
 - A CNS
 - A support worker
 - Someone else (please describe with reference to tumour site(s))
- A care plan is produced as a result of the Holistic Needs Assessment
- The patient receives a copy of the care plan
- The care plan is shared with the patient's GP
- The care plan is sent to other relevant healthcare and support professionals
- Other – please specify

2. If the care plan is sent to the patient's GP, what is your understanding of if/how this is used in primary care e.g. to support Cancer Care Reviews – please specify with reference to tumour site(s)

Free text box.

3. Please provide details of any templates or tools to undertake the Holistic Needs Assessment (e.g. Macmillan eHNA, a Distress Thermometer, other holistic needs assessment tools). Please specify with relation to tumour site(s)

Free text box.

4. How do you collect and record Holistic Needs Assessment and Care Plan data?

Tick boxes broken down by tumour site and tick each option relevant out of the following: eHNA; Infoflex; Somerset; Manually; We do not collect this data; Other IT system (please describe with reference to tumour site(s)).

TREATMENT SUMMARY

1. Number of Treatment Summaries produced in Q4 2016/17 for each tumour type.
2. When is the Treatment Summary created?

Tick boxes broken down by tumour site and tick each option relevant out of the following:

- At the end of each cycle of treatment
- At the end of final treatment
- Other – please specify with reference to tumour site(s)

3. What does the Treatment Summary include?

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Tick boxes broken down by tumour site and tick each option relevant out of the following:

- Details of treatment (e.g. surgery, drugs, therapy)
 - Details of possible side effects
 - Details of possible consequences of treatment, including late consequences
 - Signs and symptoms of recurrence to look out for
 - Advice on how to manage consequences of treatment
 - Actions that need to be taken by primary care
 - Details of who to contact in secondary care for any questions or concerns
 - Other – please specify with reference to tumour site(s)
4. Does the Treatment Summary include or reference the most recent Holistic Needs Assessment and Care Plan?

Boxes to provide an affirmative response for each tumour site.

5. Who creates the Treatment Summary and how is it shared?

Tick boxes broken down by tumour site and tick each option relevant out of the following:

- Clinician e.g. oncologist, surgeon, physician, radiographer, CNS creates the Treatment Summary Support worker creates the Treatment Summary
 - Treatment Summary is electronically sent to GP
 - Treatment Summary is electronically sent to patient
 - Treatment Summary is stored in patient's file
 - Treatment Summary is sent by post to GP
 - Treatment Summary is sent by post to patient
 - Patient accesses Treatment Summary through a patient portal or similar
 - Treatment Summary is shared with the patient through a conversation with a healthcare professional
 - If through a conversation, who has this conversation – please specific with reference to tumour site(s) – free text box
 - GP has direct access to Treatment summary via patient records
 - Other – please specify with reference to tumour site(s)
6. What is your understanding of if/how the Treatment Summary is used in primary care e.g. to support Cancer Care Reviews – please provide details with reference to tumour site(s)

Free text box.

HEALTH & WELLBEING EVENT OR SIMILAR

1. This organisation:

Tick boxes broken down by tumour site and tick each option relevant out of the following:

- Delivers Health and Wellbeing Events or similar
 - Refers patients to events/courses run by others
 - Provides written information
 - Other – please specify with reference to tumour site(s)
2. If your organisation delivers or refers patients to events/courses, when is this offered:
- Tick boxes broken down by tumour site and tick each option relevant out of the following:*
- Near diagnosis

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- During treatment
 - At the end of final treatment
 - When the patient asks for it
 - Other – please specify with reference to tumour site(s)
3. If your organisation delivers or refers patients to events/courses, is the event/course or similar:
Tick boxes broken down by tumour site and tick each option relevant out of the following:
- Tumour site specific
 - Open to all patients with cancer
 - Open to a more general group of patients e.g. those with long term conditions
4. If your organisation delivers or refers patients to events/courses, what is covered during the session(s)
Tick boxes broken down by tumour site and tick each option relevant out of the following:
- Information on physical activity
 - Information about work
 - Information about finances
 - Information about diet and nutrition
 - Information on psychological wellbeing
 - Information on coping with fatigue
 - Information on symptoms of recurrence Information on anxiety and depression
 - Information on the consequences of treatment/late effects
 - Information on what to expect from follow up care in the community/GP
 - Information on social care support
 - Other topics/themes/activities covered – please provide details with reference to tumour site(s)
5. If your organisation refers patients to events/courses run by others please provide details of the organisation who delivers the event if possible – with reference to tumour site(s)
Free text box.
6. How many patients attended Health and Wellbeing Events or similar in Quarter 4 2016/2017 (1 January 2017 – 31 March 2017) for each tumour type.
7. Does your CCG actively commission the Recovery Package (or elements of it) WHICH MIGHT INCLUDE contracts, performance targets, incentive schemes such as CQUIN AND IF SO WHAT ARE THE ARRANGEMENTS
Boxes to provide a yes or no answer for each tumour site along with free text boxes for each response.

ADDITIONAL INFORMATION

Free text boxes to provide further details for the Holistic Needs Assessment, Treatment Summary and Health and Wellbeing Event or Similar for each of the following questions, giving tumour group details where applicable:

- Challenges involved in collecting the data and if/how they have been overcome
- Steps taken to ensure consistency and robustness of data collection
- Examples of what has worked well in terms of data collection

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- Examples of how you have used data to inform improvements in care/service delivery
- Examples of what has worked well in piloting or implementing the Recovery Package
- Barriers to piloting/implementing the Recovery Package and how these have/might be overcome
- Any other information you think would be useful to share

STRATIFIED FOLLOW-UP PATHWAY – SURVEY

This survey aims to provide a baseline of activity for Stratified Pathways. We are aware that there are likely to be variation in how stratified pathways have been piloted and implemented and for this reason we have a particular focus on the Supported Self Management Pathway. The survey will also support:

- the identification of options for improving consistency and robustness of local data collection on activity to enable national/local monitoring and reporting
- highlighting of areas for improvement at local and national levels
- the capture of examples of how stratified pathways have been implemented and how challenges have been overcome that can be shared with others

We appreciate that not all the information may be available; a key part of this exercise is to understand this so that improvements can be supported. Where data is not available, we would ask you to complete the field with the text 'not available'.

CANCER ALLIANCES SHOULD PLEASE RETURN – *one Stratified Follow-Up Pathway Survey for each provider trust.*

Collated surveys should be sent to [Frontline Consultants] by 20th October 2017

We would like to thank you for your support in helping to create the baseline. Should you have any questions on the survey/its operation or require any support please contact: [Frontline Consultants].

1. Name of trust.
2. Name/title of individual(s) completing the survey.
3. Number of patients receiving first definitive treatment within 31 days of diagnosis* in 2016/17 Quarter 4 (January 1st 2017 to March 31st 2017) for breast, colorectal, prostate, other (please specify cancer type and number).
*This is a proxy only as it is recognised that patients will not always receive Recovery Package interventions at the end of treatment within the same quarter as decision to treat.
4. Number of patients stratified on to a Supported Self Management Follow-Up Pathway for breast, colorectal, prostate, other (please specify cancer type and number). (*a collaborative partnership between patients and health professionals that empowers the individual to self-manage their condition and well-being without the need to participate in routine follow-up appointments. Supported self-management pathways aim to give individuals the confidence and capability to move on from their cancer diagnosis and treatment - and live actively and well*).

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5. Are criteria/protocols in place for stratifying patients on to a Supported Self Management Follow-Up Pathway? For breast, colorectal, prostate, other.
6. If you have an agreed target/model for the proportion of patients who are likely to be suitable for a Supported Self Management Follow-Up Pathway please give the target proportion as a percentage (if available). For breast, colorectal, prostate, other.
7. Which of the following features are included in the Supported Self Management Follow-Up Pathway. For breast, colorectal, prostate, other.
Tick boxes broken down by tumour site and tick each option relevant out of the following:
 - Implementation/continuation of all Recovery Package Interventions
 - A remote monitoring system to manage on-going surveillance tests
 - Contact details/helpline for the specialist team
 - Rapid re-access to the specialist team as required
 - Co-ordination between secondary and primary care
 - Other (please specify with reference to tumour site(s))
8. The number of patients on a Supportive and Palliative Care Pathway (*clinician led with palliative care input as required. This may be led/delivered by secondary or primary care*). For breast, colorectal, prostate, other.
9. The number of patients on any other follow-up pathway. For breast, colorectal, prostate, other.
10. Does your CCG actively commission the delivery of Stratified Follow-Up Pathways WHICH MIGHT INCLUDE contracts, performance targets, incentive schemes such as CQUIN AND IF SO WHAT ARE THE ARRANGEMENTS
Boxes to provide a yes or no answer for breast, colorectal, prostate, other.along with free text boxes for each response.

ADDITIONAL INFORMATION

Free text boxes for each tumour site to provide further details in relation to data collection for Stratified Pathways for each of the following questions:

- Challenges involved in collecting the data and if/how they have been overcome
- Steps taken to ensure consistency and robustness of data collection
- Examples of what has worked well in terms of data collection
- Examples of how you have used data to inform improvements in care/service delivery
- Examples of any outcome measures used to evidence/monitor/measure impact/benefits
- Examples of what has worked well in piloting or implementing Stratified Follow-Up Pathways
- Barriers to piloting/implementing Stratified Follow-Up Pathways and how these have/might be overcome
- Any other information you think would be useful to share.

CANCER CARE REVIEW - PRACTICE LEVEL DATA

1. Practice Name
2. Number of registered patients diagnosed with cancer during 2016/2017 Quarter 4 (1 January 2017 – 31 March 2017) for each tumour type.

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3. Number of patients who received at least 1 Cancer Care Review during 2016/2017 Q4 (1 January 2017 – 31 March 2017) for each tumour type.
4. How many were:
Boxes to provide data for each tumour site for the following:
 - Undertaken by a GP as part of a standard appointment
 - Undertaken by a GP as part of an extended appointment
 - Undertaken by a Practice Nurse within a standard appointment
 - Undertaken by a Practice Nurse as part of a specialist clinic (e.g. extended appointment by Practice Nurse who has received specialist training)
 - Undertaken by a CNS working out in the community alongside GP practices
 - Don't know
 - Other – please specify with reference to tumour site(s)
5. What does the Cancer Care Review involve and when does it take place
Tick boxes broken down by tumour site and tick each option relevant out of the following:
 - Assessment/reassessment of the person's holistic (clinical and non clinical needs) in light of the cancer, consequences of treatment, current or potential
 - Updated care planning as a result of the assessment
 - The provision of additional primary care support as required
 - Signposting, navigation, referral to other sources of information and support and enablement of self-managed activity
 - It is offered/provided at the transition from secondary to primary care
 - It is offered/provided when the patient presents with changing holistic needs
 - It is offered/provided when the patient asks for it
 - It is offered/provided at scheduled, defined intervals
6. Holistic Needs Assessments/Care Plans and Treatment Summaries are reliably received from secondary care
Boxes to provide an affirmative response for each tumour type.
7. Holistic Needs Assessments/Care Plans and Treatment Summaries from secondary care provide the necessary information to inform a holistic Cancer Care Review
Boxes to provide an affirmative response for each tumour type.
8. Where is Cancer Care Review data recorded – please specify with reference to tumour site(s) if appropriate.
Free text box.
9. Does your CCG actively commission the delivery of Cancer Care Reviews WHICH MIGHT INCLUDE contracts, performance targets, incentive schemes such as QOF
Boxes to provide a yes or no answer along with free text box

ADDITIONAL INFORMATION

Free text box to provide further details in relation to Cancer Care Reviews for each of the following questions:

- Challenges involved in collecting the data and if/how they have been overcome
- Steps taken to ensure consistency and robustness of data collection

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- Examples of what has worked well in terms of data collection
- Examples of how you have used data to inform improvements in care/service delivery
- Examples of any outcome measures used to evidence/monitor/measure impact and/or benefits
- Examples of what has worked well in piloting or implementing Cancer Care Reviews
- Barriers to piloting/implementing Cancer Care Reviews and how these have/might be overcome
- Any other information you think would be useful to share.