

**June 2019 Update on the Project to develop LWBC Metrics and Data Collection  
Including option to locally adopt metrics**

**Background**

In 2018, a group of stakeholders, including charity, software provider, trust and Cancer Alliance representatives, formed a consensus on ten LWBC metric definitions so that Cancer Alliances, MDTs and other organisations would be able to consistently monitor progress on LWBC transformation. The consensus was needed in order to formally set national metrics for LWBC which is a major priority for cancer services, commissioners and Alliances. In order to support robust LWBC data collection, eight new LWBC data items for the Cancer Outcomes and Services Dataset (COSD) v9 dataset were proposed in late 2018, which have now passed through consultation, and are awaiting formal release in Autumn 2019, with data submission to Public Health England (PHE) commencing from Q1 2020/21 (see below for more information).

In the meantime, Trusts and Alliances have provided 'temperature check' and quarterly transformation plan assurance data (i.e. not patient-level data) that has enabled significant progress from the [Jan-Mar 2017 Baseline activity](#) to be demonstrated.

2019/20 is therefore a very important transition year, with trusts making preparations for the adoption of COSD v9 data collection (once announced in September 2019) on which to base future LWBC metrics. From 2020/21 onwards, the range and quality of monitoring data for the transformation of services for people living with and beyond cancer will be greatly enhanced.

**Next Steps 2019/20 and beyond**

1. 2019/20 Formal quarterly assurance reporting by Cancer Alliances to Regions

Cancer Alliances are required to report through the existing NHS England Regional quarterly assurance process on their progress towards the personalised care and personalised stratified follow up (PSFU) objectives in the LTP and the 2019/20 NHS Planning Guidance, as per targets within their own Alliance plans.

In 2019/20 this assurance process will focus on:

- a. Estimate of the **% of people treated for breast cancer who are to be followed up by supported self-management.**
- b. Whether services are offering **Personalised Care interventions** for breast, prostate and colorectal cancer patients
- c. **Audit tool of implementation of PSFU protocols in breast cancer.**  
This audit will focus on quality, patient experience and the delivery of

the key personalised care interventions in cancer (personalised care and support planning based on HNA, end of treatment summary and health and wellbeing information and support). Consultation on the format of the audit tool is currently taking place.

- d. Number and % of **trusts with PSFU protocols** for breast, colorectal and prostate cancer
- e. Number and % **of trusts with remote monitoring systems** for breast, colorectal and prostate PSFU pathways;
- f. **Holistic Needs Assessment (HNA) activity data**, provided via PHE from the COSD database (to be made available via the CancerStats2 portal by early July 2019) as a proxy measure of roll out of Personalised Care and Support Planning (PCSP). CADEAS will provide a short narrative report each quarter, shortly after the data release on CancerStats2. This data will cover metric LWBC004;
- g. Number and % of **trusts submitting breast, prostate and colorectal HNA data** for COSD
- h. Estimate of **outpatient slots saved when PSFU was introduced** (however long ago this happened)

## 2. 2019/20 Local LWBC activity and outcome reporting (in addition to quarterly assurance indicators above)

Alliances and Trusts should continue to work together on how best to provide all local partners with LWBC progress reports that support ongoing LWBC transformation work in 2019/20. Organisations wishing to use the [LWBC metrics definitions](#) in this pack in 2019/20 are free to do so, but should be aware that they have not been through the formal NHS Data Coordination Board approval process and are therefore **subject to change**. If any organisation wishes to use a subset of the ten, suggested metrics are marked in the [table](#) overleaf.

Important note: as we approach the introduction of COSD v9 requirements in the next year, we will re-visit these LWBC metric definitions and aim to obtain Data Coordination Board approval and to release formal definitions which include use of COSD v9 data.

## 3. From 2020/21 New Cancer Outcomes and Services Dataset (COSD) v9 data collection requirements

Pending final approval, PHE will be implement changes to the COSD database from **April 2020** (COSD v9) that will require secondary care to submit additional information about LWBC interventions with people diagnosed with cancer, including when and who offered/completed HNA and PCSP and date(s) of End of Treatment Summaries. There will also be a risk factor assessment on Physical Activity. Allowing

for transition to the new requirements, the first month when all trusts should be submitting the new LWBC items is July 2020. Important: there will be no COSD v9 requirements around personalised stratified follow up.

#### 4. 2019/20 Data collection changes in preparation for 2020/21 COSD v9

The changes to COSD will require trusts to implement new data collection across the latter part of 2019/20 to meet these new requirements. It is strongly recommended that plans are made to adopt these changes and begin data collection at the earliest opportunity. IT suppliers will need to provide the right functionality in their systems (this has been part of the COSD v9 consultation process conducted by PHE). PHE will provide full details in September 2019 once formal approval of the v9 dataset has been given. Contact details for questions about COSD are [here](#) or email Andy Murphy, Head of Cancer Datasets [Andrew.murphy@phe.gov.uk](mailto:Andrew.murphy@phe.gov.uk).

#### **How the metrics were developed**

The LWBC metric definitions were developed as follows:

- Example metrics already in use or recommended by Macmillan Cancer Support and various Cancer Alliances were collated and discussed at an expert workshop on 11<sup>th</sup> June 2018 involving representatives from NHS England, Cancer Alliances, Trust informatics departments, IT providers and Macmillan.
- A broad consensus was reached at the workshop and the first outline draft of eight metric definitions was shared with workshop participants in June.
- CDAAG (Cancer Data Analysis Advisory Group) also reviewed the outline drafts in July 2018.
- CDAAG advice plus further feedback from the workshop participants led to the first detailed draft of ten metric definitions. These were shared with workshop participants and LWBC leads in Cancer Alliances (and anyone they wished to share the documents with) in early August 2018 and comments were invited by 31<sup>st</sup> August 2018.
- Analysis of the 50+ responses received led to further refinement of the definitions resulting in the Version 0.9 [draft ten metrics](#) included in this document.

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**Draft Living With and Beyond Cancer metrics SUBJECT TO CHANGE**

***bold\*** = suggested metrics if a trust or alliance wishes to use a smaller subset*

	Metric number	Metric short name	Metric full name
<b>Personalised Stratified Follow Up</b>	<b>LWBC001A*</b> and LWBC001B	<a href="#"><u>Personalised Stratified Follow Up for Breast Cancer</u></a>	The percentage of people with breast cancer who have been initially stratified to (A) supported self-managed follow up and (B) scheduled, usually clinic-based, professional-led follow up.
	<b>LWBC002A</b> and LWBC002B	<a href="#"><u>Personalised Stratified Follow Up for Colorectal Cancer</u></a>	The percentage of people with colorectal cancer who have been initially stratified to (A) supported self-managed follow up and (B) scheduled, usually clinic-based, professional-led follow up.
	<b>LWBC003A</b> and LWBC003B	<a href="#"><u>Personalised Stratified Follow Up for Prostate Cancer</u></a>	The percentage of people with prostate cancer who have been initially stratified to (A) supported self-managed follow up and (B) scheduled, usually clinic-based, professional-led follow up.
<b>Personalised Care interventions</b> (Formerly known as the 'Recovery Package')	LWBC004A, LWBC004B, LWBC004C, LWBC004D, <b>LWBC004T*</b>	<a href="#"><u>Holistic Needs Assessments for people living with and beyond cancer</u></a>	The number of completed Holistic Needs Assessments (HNA) at cancer diagnosis, treatment and other time points: A. Initial cancer diagnosis B. Start of treatment C. End of treatment D. Other (total of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions) T. Total of A + B+ C + D
	LWBC005	<a href="#"><u>Timely Holistic Needs Assessments for people living with and beyond cancer</u></a>	The proportion of people who have at least one completed HNA carried out within 31 days of decision to treat for 1 <sup>st</sup> cancer treatment.
	LWBC006A, LWBC006B, LWBC006C, LWBC006D, <b>LWBC006T*</b>	<a href="#"><u>Personalised Care and Support Plans for people living with and beyond cancer</u></a>	The number of completed Personalised Care and Support Plans at cancer diagnosis, treatment and other time points: A. Initial cancer diagnosis B. Start of treatment C. End of treatment D. Other (total of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions) T. Total of A + B+ C + D

**Draft Living With and Beyond Cancer metrics SUBJECT TO CHANGE**

***bold\*** = suggested metrics if a trust or alliance wishes to use a smaller subset*

	Metric number	Metric short name	Metric full name
<b>Personalised Care interventions</b> (Formerly known as the 'Recovery Package')	LWBC007A, LWBC007B, LWBC007C, LWBC007D, <b>LWBC007T*</b>	<a href="#">Holistic Needs Assessments leading to Personalised Care and Support Plans for people living with and beyond cancer</a>	The percentage of Holistic Needs Assessments that lead to completed Personalised Care and Support Plans for people affected by cancer at different points in the cancer pathway: A. Initial cancer diagnosis B. Start of treatment C. End of treatment D. Other (total of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions) T. Total of A + B+ C + D
	<b>LWBC008*</b>	<a href="#">End of Treatment Summaries for people living with and beyond cancer</a>	The percentage of people treated for cancer with a completed End of Treatment Summary
	LWBC009	<a href="#">Health and Wellbeing Information and Support for people affected by cancer</a>	The proportion of a Cancer Alliance population with a comprehensive, accessible Health and Wellbeing Information and Support offer that meets the needs of people affected by cancer (including carers) from diagnosis onwards and which increases their ability to manage their own health and wellbeing.
	LWBC010	<a href="#">Cancer care reviews in primary care (as per current QoF indicator)</a>	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. (as per current QoF indicator)

<b><u>Draft Metric LWBC001 for Personalised Stratified Follow Up for Breast Cancer</u></b>	
Metric number	LWBC001A and LWBC001B
Metric short name	Personalised Stratified Follow Up for Breast Cancer
Metric full name	The percentage of people with breast cancer who have been initially stratified to: (A) supported self-managed follow up and (B) scheduled, usually clinic-based, professional-led follow up.
Rationale	<p>The NHS England Long Term Plan<sup>1</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transforming follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing information and support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions:</p> <p><i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p><i>“After treatment, patients will move to a follow-up pathway that suits their needs, and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred. This stratified follow-up approach will be established in all trusts for breast cancer in 2019, for prostate and colorectal cancers in 2020 and for other cancers where clinically appropriate by 2023.”</i></p> <p>It is an NHS England 2019/20 planning guidance target for all Cancer Alliances to ensure full implementation of breast cancer personalised stratified follow up by the end of 2019/20, so that from April 2020 approximately two-thirds of people who finish treatment for breast cancer are on a supported self-management follow-up pathway.</p> <p>Improving cancer follow up is a continuation of one of the key ambitions in the report, <i>Achieving world-class cancer outcomes: a strategy for England</i></p>

<sup>1</sup> <https://www.england.nhs.uk/long-term-plan/>

<b><u>Draft Metric LWBC001 for Personalised Stratified Follow Up for Breast Cancer</u></b>	
	<p>2015-2020, published by the Independent Cancer Taskforce in July 2015<sup>2</sup>. The Taskforce recommended that all providers were incentivised to implement stratified follow-up pathways of care for people treated for breast cancer.</p> <p>It was an NHS England 2018/19 planning guidance target for all Cancer Alliances to have in place clinically agreed protocols for stratifying breast cancer patients and a system for remote monitoring by March 2019.</p>
Definition	<p>The percentage of people who had First Definitive Treatment for breast cancer who it has been agreed are to be followed up initially after treatment by either (A) supported self-management or by (B) scheduled, usually clinic-based, professional-led appointments.</p> <p>(B) includes being initially assigned to any form of pre-planned and not solely patient-triggered appointments, which may include a telephone follow up clinic schedule or primary-care led follow up where these have been locally agreed.</p> <p>Note: Personalisation of follow up involves personalised care and support planning based on holistic needs assessment, so that a person's follow up pathway (whether supported self-management or professional-led) meets their holistic needs and is agreed through shared decision-making. An End of Treatment Summary must also be provided.</p>
Data source	NHS Trusts
Indicator production	To be decided locally.
Definition of numerator	<p>LWBC001A</p> <p>The number of people suitable for post-treatment stratification within the reporting period who, at the first time they are stratified for follow up, have been stratified to supported self-managed follow up following treatment for breast cancer.</p> <p>Supported self-managed follow up (sometimes called 'patient triggered' or 'open access' follow up) involves:</p> <ul style="list-style-type: none"> <li>• Personalised Care and Support Planning (based on holistic needs assessment) including a joint decision between the person and their cancer team to enter supported self-managed follow up;</li> <li>• Access to a patient education and support event or course, to prepare the person for the transition to supported self-management, including advice on healthy lifestyle and physical activity and/or support and information for self-management and health and wellbeing;</li> <li>• Information on potential markers of recurrence/secondary cancers and information on what to do in these circumstances;</li> </ul>

<sup>2</sup> [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<b><u>Draft Metric LWBC001 for Personalised Stratified Follow Up for Breast Cancer</u></b>	
	<ul style="list-style-type: none"> <li>• Access back to the cancer team at any time - A key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent;</li> <li>• Information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years;</li> <li>• Ongoing surveillance for cancer by 'Remote Monitoring' (i.e. 'all clear' results of routine surveillance tests/scans are communicated via post, phone or patient portal)</li> <li>• Referral for rehabilitation and support services such as psychology, return to work, financial advice, physical activity, managing long-term consequences of treatment</li> <li>• Information shared with the person and their GP practice, including an End of Treatment Summary.</li> </ul> <p>LWBC001B                      The number of people suitable for post-treatment stratification within the reporting period who, at the first time they are stratified for follow up, have been stratified to scheduled, usually clinic-based, professional-led follow up following treatment for breast cancer.</p> <p>The choice of whether a person is stratified to self-managed follow up or scheduled professional-led follow up is made in line with local clinically-agreed protocols, and is a shared decision with the person.</p>
Source of numerator	Trust cancer systems or other data source
Definition of denominator	Total number of people within the reporting period undergoing First Definitive Treatment for breast cancer after being referred for cancer treatment and care within organisation. (Note that 'First Definitive Treatment' is as per NHS Data Dictionary therefore includes palliative care and commencement of active monitoring.)
Source of denominator	Cancer Waiting Times reports <i>Data taken from the National Cancer Waiting Times Database (CWT-db) held within Open Exeter, collated and distributed by the Analytical Service (Operations) team on behalf of NHS England</i>
Methodology	The number of people who have been initially stratified to (A) supported self-managed or (B) scheduled, usually clinic-based, professional-led follow up following treatment for breast cancer divided by the total number of people undergoing First Definitive Treatment for breast cancer
Data quality	To be determined
Unit	Percentage
Year type	Financial
Frequency and data lag	Quarterly. Data lag to be determined.
Interpretation	Interpretation of the metric should be made with care as there is no requirement for the percentage of people on supported self-managed follow up to achieve any particular target level.

<b><u>Draft Metric LWBC001 for Personalised Stratified Follow Up for Breast Cancer</u></b>	
	<p>It should not be assumed that where one organisation (or one time period) has a higher proportion of people on supported self-managed follow up that this is 'better' performance than another.</p> <p>The percentage of people on either pathway will vary geographically according to</p> <ul style="list-style-type: none"> <li>• the application of local clinical criteria</li> <li>• individual choice</li> <li>• individual needs.</li> </ul> <p>However 2018/19 and 2019/20 planning guidance has indicated that around two-thirds of people with breast cancer would be expected to be on a supported self-managed follow up pathway. Note that the <i>Baseline Survey of LWBC activity Jan-Mar 2017</i><sup>3</sup> indicated that in trusts already using supported self-managed follow up in breast cancer, the proportion of people on supported self-managed follow up was 67%, and the majority of trusts had targets of between 70 and 89% for supported self-management.</p> <p>The numerator figure may be skewed by various factors, including referrals between secondary and tertiary centres, which are difficult to mitigate.</p> <p>The use of First Definitive Treatment as the denominator is a proxy measure for the number of people diagnosed with breast cancer. There are a number of problems inherent in using the First Definitive Treatment figure as the denominator, including that it is probably an underestimate, and that the cohort of people differs from those counted for the numerator. However, at this time, there is no suitable alternative to using First Definitive Treatment.</p> <p>LWBC001A and LWBC001B would never be expected to add up to exactly 100% and their sum total may exceed 100% for various reasons.</p>
Further information	<ul style="list-style-type: none"> <li>• There are equivalent metrics for colorectal and prostate cancer.</li> <li>• Trusts or Alliances should determine locally: - <ul style="list-style-type: none"> <li>○ what the criteria are for entry into supported self-managed follow up and into professional-led follow up</li> <li>○ what the protocols are for managing people on either pathway</li> <li>○ what the system is for ensuring a safe remote monitoring system for people on the self-managed pathway.</li> </ul> </li> <li>• Locally, where personalised stratified follow up is in place for other cancer types, measurement using these same definitions is encouraged. It is acknowledged that follow up in other cancer types may involve more than 2 types of stratification.</li> </ul>
References	<p>Innovation to implementation: Stratified pathways of care for people living with or beyond cancer. A 'how to guide' (NHS Improvement, 2013)  <a href="https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf">https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf</a>  <i>Note a new handbook will be produced by NHS England in 2019/20.</i></p>

<sup>3</sup> <https://www.england.nhs.uk/publication/living-with-and-beyond-cancer-baseline-activity/>

**Draft Metric LWBC001 for Personalised Stratified Follow Up for Breast Cancer**

A selection of other documents helpful for personalised stratified follow up implementation can be found on the 'FutureNHS Collaboration' platform Cancer Alliances online portal – please contact [england.cancerpolicy@nhs.net](mailto:england.cancerpolicy@nhs.net) for access.

<b><u>Draft Metric LWBC002 for Personalised Stratified Follow Up for Colorectal Cancer</u></b>	
Metric number	LWBC002A and LWBC002B
Metric short name	Personalised Stratified Follow Up for Colorectal Cancer
Metric full name	The percentage of people with colorectal cancer who have been initially stratified to: (A) supported self-managed follow up and (B) scheduled, usually clinic-based, professional-led follow up.
Rationale	<p>The NHS England Long Term Plan<sup>4</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transforming follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing information and support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions:</p> <p><i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p><i>“After treatment, patients will move to a follow-up pathway that suits their needs, and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred. This stratified follow-up approach will be established in all trusts for breast cancer in 2019, for prostate and colorectal cancers in 2020 and for other cancers where clinically appropriate by 2023.”</i></p> <p>It is an NHS England 2019/20 planning guidance target for all Cancer Alliances to have in place clinically-agreed protocols for stratifying prostate and colorectal cancer patients and systems for remote monitoring by the end of 2019/20.</p> <p>Improving cancer follow up is a continuation of one of the key ambitions in the report, <i>Achieving world-class cancer outcomes: a strategy for England</i></p>

<sup>4</sup> <https://www.england.nhs.uk/long-term-plan/>

<b><u>Draft Metric LWBC002 for Personalised Stratified Follow Up for Colorectal Cancer</u></b>	
	2015-2020, published by the Independent Cancer Taskforce in July 2015 <sup>5</sup> . The Taskforce recommended that all providers were incentivised to implement stratified follow-up pathways of care for patients treated for breast cancer, followed by others including colorectal and prostate.
Definition	<p>The percentage of people who had First Definitive Treatment for colorectal cancer who it has been agreed are to be followed up initially after treatment by either (A) supported self-management or by (B) scheduled, usually clinic-based, professional-led appointments.</p> <p>(B) includes being initially assigned to any form of pre-planned and not solely patient-triggered appointments, which may include a telephone follow up clinic schedule or primary-care led follow up where these have been locally agreed.</p> <p>Note: Personalisation of follow up involves personalised care and support planning based on holistic needs assessment, so that a person's follow up pathway (whether supported self-management or professional-led) meets their holistic needs and is agreed through shared decision-making. An End of Treatment Summary must also be provided.</p>
Data source	NHS Trusts
Indicator production	To be decided locally.
Definition of numerator	<p>LWBC002A</p> <p>The number of people suitable for post-treatment stratification within the reporting period who, at the first time they are stratified for follow up, have been stratified to supported self-managed follow up following treatment for colorectal cancer.</p> <p>Supported self-managed follow up (sometimes called 'patient triggered' or 'open access' follow up) involves:</p> <ul style="list-style-type: none"> <li>• Personalised Care and Support Planning (based on holistic needs assessment) including a joint decision between the person and their cancer team to enter supported self-managed follow up;</li> <li>• Access to a patient education and support event or course, to prepare the person for the transition to supported self-management, including advice on healthy lifestyle and physical activity and/or support and information for self-management and health and wellbeing;</li> <li>• Information on potential markers of recurrence/secondary cancers and information on what to do in these circumstances;</li> <li>• Access back to the cancer team at any time - A key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent;</li> </ul>

<sup>5</sup> [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<b><u>Draft Metric LWBC002 for Personalised Stratified Follow Up for Colorectal Cancer</u></b>	
	<ul style="list-style-type: none"> <li>Information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years;</li> <li>Ongoing surveillance for cancer by 'Remote Monitoring' (i.e. 'all clear' results of routine surveillance tests/scans are communicated via post, phone or patient portal)</li> <li>Referral for rehabilitation and support services such as psychology, return to work, financial advice, physical activity, managing long-term consequences of treatment</li> <li>Information shared with the person and their GP practice, including an End of Treatment Summary.</li> </ul> <p>LWBC002B</p> <p>The number of people suitable for post-treatment stratification within the reporting period who, at the first time they are stratified for follow up, have been stratified to scheduled, usually clinic-based, professional-led follow up following treatment for colorectal cancer.</p> <p>The choice of whether a person is stratified to self-managed follow up or scheduled professional-led follow up is made in line with local clinically-agreed protocols, and is a shared decision with the person.</p>
Source of numerator	Trust cancer systems or other data source
Definition of denominator	Total number of people within the reporting period undergoing First Definitive Treatment for colorectal cancer after being referred for cancer treatment and care within organisation. (Note that 'First Definitive Treatment' is as per NHS Data Dictionary therefore includes palliative care and commencement of active monitoring.)
Source of denominator	Cancer Waiting Times reports <i>Data taken from the National Cancer Waiting Times Database (CWT-db) held within Open Exeter, collated and distributed by the Analytical Service (Operations) team on behalf of NHS England</i>
Methodology	The number of people who have been initially stratified to (A) supported self-managed or (B) scheduled, usually clinic-based, professional-led follow up following treatment for colorectal cancer divided by the total number of people undergoing First Definitive Treatment for colorectal cancer
Data quality	To be determined
Unit	Percentage
Year type	Financial
Frequency and data lag	Quarterly. Data lag to be determined.
Interpretation	Interpretation of the metric should be made with care as there is no requirement for the percentage of people on supported self-managed follow up to achieve any particular target level.

<b><u>Draft Metric LWBC002 for Personalised Stratified Follow Up for Colorectal Cancer</u></b>	
	<p>It should not be assumed that where one organisation (or one time period) has a higher proportion of people on supported self-managed follow up that this is 'better' performance than another.</p> <p>The percentage of people on either pathway will vary geographically according to</p> <ul style="list-style-type: none"> <li>• the application of local clinical criteria</li> <li>• individual choice</li> <li>• individual needs.</li> </ul> <p>However, evidence has indicated that around a third to a half of people with colorectal cancer would be expected to be on a supported self-managed follow up pathway. Note that the National Cancer Survivorship Initiative (2013) suggested 45% on supported self-managed follow up, and the <i>Baseline Survey of LWBC activity Jan-Mar 2017</i><sup>6</sup> indicated that, in trusts already using supported self-managed follow up in colorectal cancer, the proportion of people on supported self-managed follow up was 49%, and the majority of trusts had targets of between 40 and 49% for supported self-management.</p> <p>The numerator figure may be skewed by various factors, including referrals between secondary and tertiary centres, which are difficult to mitigate.</p> <p>The use of First Definitive Treatment as the denominator is a proxy measure for the number of people diagnosed with colorectal cancer. There are a number of problems inherent in using the First Definitive Treatment figure as the denominator, including that it is probably an underestimate, and that the cohort of people differs from those counted for the numerator. However, at this time, there is no suitable alternative to using First Definitive Treatment.</p> <p>LWBC002A and LWBC002B would never be expected to add up to exactly 100% and their sum total may exceed 100% for various reasons.</p>
Further information	<ul style="list-style-type: none"> <li>• There are equivalent metrics for breast and prostate cancer.</li> <li>• Trusts or Alliances should determine locally: - <ul style="list-style-type: none"> <li>○ what the criteria are for entry into supported self-managed follow up and into professional-led follow up</li> <li>○ what the protocols are for managing people on either pathway</li> <li>○ what the system is for ensuring a safe remote monitoring system for people on the self-managed pathway.</li> </ul> </li> <li>• Locally, where personalised stratified follow up is in place for other cancer types, measurement using these same definitions is encouraged. It is acknowledged that follow up in other cancer types may involve more than 2 types of stratification.</li> </ul>
References	<p>Innovation to implementation: Stratified pathways of care for people living with or beyond cancer. A 'how to guide' (NHS Improvement, 2013)  <a href="https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf">https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf</a></p>

<sup>6</sup> <https://www.england.nhs.uk/publication/living-with-and-beyond-cancer-baseline-activity/>

**Draft Metric LWBC002 for Personalised Stratified Follow Up for Colorectal Cancer**

*Note a new handbook will be produced by NHS England in 2019/20.*

A selection of other documents helpful for personalised stratified follow up implementation can be found on the 'FutureNHS Collaboration' platform Cancer Alliances online portal – please contact [england.cancerpolicy@nhs.net](mailto:england.cancerpolicy@nhs.net) for access.

<b><u>Draft Metric LWBC003 for Personalised Stratified Follow Up for Prostate Cancer</u></b>	
Metric number	LWBC003A and LWBC003B
Metric short name	Personalised Stratified Follow Up for Prostate Cancer
Metric full name	The percentage of people with prostate cancer who have been initially stratified to: (A) supported self-managed follow up and (B) scheduled, usually clinic-based, professional-led follow up.
Rationale	<p>The NHS England Long Term Plan<sup>7</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transforming follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing information and support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions:</p> <p><i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p><i>“After treatment, patients will move to a follow-up pathway that suits their needs, and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred. This stratified follow-up approach will be established in all trusts for breast cancer in 2019, for prostate and colorectal cancers in 2020 and for other cancers where clinically appropriate by 2023.”</i></p> <p>It is an NHS England 2019/20 planning guidance target for all Cancer Alliances to have in place clinically-agreed protocols for stratifying prostate and colorectal cancer patients and systems for remote monitoring by the end of 2019/20.</p> <p>Improving cancer follow up is a continuation of one of the key ambitions in the report, <i>Achieving world-class cancer outcomes: a strategy for England</i></p>

<sup>7</sup> <https://www.england.nhs.uk/long-term-plan/>

<b><u>Draft Metric LWBC003 for Personalised Stratified Follow Up for Prostate Cancer</u></b>	
	2015-2020, published by the Independent Cancer Taskforce in July 2015 <sup>8</sup> . The Taskforce recommended that all providers were incentivised to implement stratified follow-up pathways of care for people treated for breast cancer, followed by others including colorectal and prostate.
Definition	<p>The percentage of people who had First Definitive Treatment for prostate cancer who it has been agreed are to be followed up initially after treatment by either (A) supported self-management or by (B) scheduled, usually clinic-based, professional-led appointments.</p> <p>(B) includes being initially assigned to any form of pre-planned and not solely patient-triggered appointments, which may include a telephone follow up clinic schedule or primary-care led follow up where these have been locally agreed. Primary-care led follow up is being implemented in some areas but usually around 2 years post treatment. Therefore men suitable for primary-care led follow up will count in group B as their <u>initial</u> follow up will be via the hospital prior to being primary-care led.</p> <p>Note: Personalisation of follow up involves personalised care and support planning based on holistic needs assessment, so that a person's follow up pathway (whether supported self-management or professional-led) meets their holistic needs and is agreed through shared decision-making. An End of Treatment Summary must also be provided.</p>
Data source	NHS Trusts
Indicator production	To be decided locally.
Definition of numerator	<p>LWBC003A</p> <p>The number of people suitable for post-treatment stratification within the reporting period who, at the first time they are stratified for follow up, have been stratified to supported self-managed follow up following treatment for prostate cancer.</p> <p>Supported self-managed follow up (sometimes called 'patient triggered' or 'open access' follow up) involves:</p> <ul style="list-style-type: none"> <li>• Personalised Care and Support Planning (based on holistic needs assessment) including a joint decision between the person and their cancer team to enter supported self-managed follow up;</li> <li>• Access to a patient education and support event or course, to prepare the person for the transition to supported self-management, including advice on healthy lifestyle and physical activity and/or support and information for self-management and health and wellbeing;</li> <li>• Information on potential markers of recurrence/secondary cancers and information on what to do in these circumstances;</li> <li>• Access back to the cancer team at any time - A key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent;</li> </ul>

<sup>8</sup> [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<b><u>Draft Metric LWBC003 for Personalised Stratified Follow Up for Prostate Cancer</u></b>	
	<ul style="list-style-type: none"> <li>Information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years;</li> <li>Ongoing surveillance for cancer by 'Remote Monitoring' (i.e. 'all clear' results of routine surveillance tests/scans are communicated via post, phone or patient portal)</li> <li>Referral for rehabilitation and support services such as psychology, return to work, financial advice, physical activity, managing long-term consequences of treatment</li> <li>Information shared with the person and their GP practice, including an End of Treatment Summary.</li> </ul> <p>LWBC003B</p> <p>The number of people suitable for post-treatment stratification within the reporting period who, at the first time they are stratified for follow up, have been stratified to scheduled, usually clinic-based, professional-led follow up following treatment for prostate cancer.</p> <p>The choice of whether a person is stratified to self-managed follow up or scheduled professional-led follow up is made in line with local clinically-agreed protocols and is a shared decision with the person.</p>
Source of numerator	Trust cancer systems or other data source
Definition of denominator	Total number of people within the reporting period undergoing First Definitive Treatment for prostate cancer after being referred for cancer treatment and care within organisation. (Note that 'First Definitive Treatment' is as per NHS Data Dictionary therefore includes palliative care and commencement of active monitoring.)
Source of denominator	Cancer Waiting Times reports <i>Data taken from the National Cancer Waiting Times Database (CWT-db) held within Open Exeter, collated and distributed by the Analytical Service (Operations) team on behalf of NHS England</i>
Methodology	The number of people who have been initially stratified to (A) supported self-managed or (B) scheduled, usually clinic-based, professional-led follow up following treatment for prostate cancer divided by the total number of people undergoing First Definitive Treatment for prostate cancer
Data quality	To be determined
Unit	Percentage
Year type	Financial
Frequency and data lag	Quarterly. Data lag to be determined.
Interpretation	Interpretation of the metric should be made with care as there is no requirement for the percentage of people on supported self-managed follow up to achieve any particular target level.

<b><u>Draft Metric LWBC003 for Personalised Stratified Follow Up for Prostate Cancer</u></b>	
	<p>It should not be assumed that where one organisation (or one time period) has a higher proportion of people on supported self-managed follow up that this is 'better' performance than another.</p> <p>The percentage of people on either pathway will vary geographically according to</p> <ul style="list-style-type: none"> <li>• the application of local clinical criteria</li> <li>• individual choice</li> <li>• individual needs.</li> </ul> <p>However, evidence has indicated that around a third to a half of people with prostate cancer would be expected to be on a supported self-managed follow up pathway. Note that the National Cancer Survivorship Initiative (2013) suggested 30% on supported self-managed follow up, and the <i>Baseline Survey of LWBC activity Jan-Mar 2017</i><sup>9</sup> indicated that, in trusts already using supported self-managed follow up in prostate cancer, the proportion of people on supported self-managed follow up was 53%, and the majority of trusts had targets of between 40 and 49% for supported self-management.</p> <p>The numerator figure may be skewed by various factors, including referrals between secondary and tertiary centres, which are difficult to mitigate.</p> <p>The use of First Definitive Treatment as the denominator is a proxy measure for the number of people diagnosed with prostate cancer. There are a number of problems inherent in using the First Definitive Treatment figure as the denominator, including that it is probably an underestimate, and that the cohort of people differs from those counted for the numerator. However, at this time, there is no suitable alternative to using First Definitive Treatment.</p> <p>LWBC003A and LWBC003B would never be expected to add up to exactly 100% and their sum total may exceed 100% for various reasons.</p>
Further information	<ul style="list-style-type: none"> <li>• There are equivalent metrics for breast and colorectal cancer.</li> <li>• Trusts or Alliances should determine locally: - <ul style="list-style-type: none"> <li>○ what the criteria are for entry into supported self-managed follow up and into professional-led follow up</li> <li>○ what the protocols are for managing people on either pathway</li> <li>○ what the system is for ensuring a safe remote monitoring system for people on the self-managed pathway.</li> </ul> </li> <li>• Locally, where personalised stratified follow up is in place for other cancer types, measurement using these same definitions is encouraged. It is acknowledged that follow up in other cancer types may involve more than 2 types of stratification.</li> </ul>
References	<p>Innovation to implementation: Stratified pathways of care for people living with or beyond cancer. A 'how to guide' (NHS Improvement, 2013)  <a href="https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf">https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf</a></p>

<sup>9</sup> <https://www.england.nhs.uk/publication/living-with-and-beyond-cancer-baseline-activity/>

**Draft Metric LWBC003 for Personalised Stratified Follow Up for Prostate Cancer**

*Note a new handbook will be produced by NHS England in 2019/20.*

A selection of other documents helpful for personalised stratified follow up implementation can be found on the 'FutureNHS Collaboration' platform Cancer Alliances online portal – please contact [england.cancerpolicy@nhs.net](mailto:england.cancerpolicy@nhs.net) for access.

<b>Draft metric LWBC004 for Holistic Needs Assessment</b>	
Metric number	LWBC004A, LWBC004B, LWBC004C, LWBC004D, LWBC004T
Metric short name	Holistic Needs Assessments for people living with and beyond cancer
Metric full name	The number of completed Holistic Needs Assessments (HNA) at cancer diagnosis, treatment and other time points A. Initial cancer diagnosis B. Start of treatment C. End of treatment D. Other (total of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions) T. Total of A + B+ C + D
Rationale	<p>The <i>NHS England Long Term Plan</i><sup>10</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transform follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions;  <i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p>The interventions to support personalisation of care (formerly known as Recovery Package) will be delivered in line with the NHS Comprehensive Model for Personalised Care<sup>11</sup>.</p> <p>The NHS England 2019/20 planning guidance does not specifically mention Holistic Needs Assessments, but the Cancer Programme team guidance to Cancer Alliances states the delivery requirement:  <i>“From diagnosis, all breast/colorectal/prostate cancer patients (including secondary cancer) to have access to personalised care, including <u>needs assessment</u>, a care plan and health and wellbeing information and support”</i> and an additional requirement if funding allows:</p>

<sup>10</sup> <https://www.england.nhs.uk/long-term-plan/>

<sup>11</sup> <https://www.england.nhs.uk/personalisedcare/>

<b>Draft metric LWBC004 for Holistic Needs Assessment</b>	
	<p><i>“Make the following available to patients with cancer types other than breast, prostate and colorectal: <u>Holistic needs assessment</u>, personalised care and support plan, end of treatment summary and health and wellbeing information and support.”</i></p> <p>Improving cancer care from diagnosis was one of the key ambitions in the report, <i>Achieving world-class cancer outcomes: a strategy for England 2015-2020</i>, published by the Independent Cancer Taskforce in July 2015. The Taskforce recommended that NHS England should accelerate the commissioning of services for people living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the ‘Recovery Package’ by 2020, [including] <u>a holistic needs assessment</u> and a written individualised care and support plan at key points across the pathway.</p> <p>HNA therefore remains a fundamental component of the personalisation of cancer care, and should be very widely conducted as the basis for meaningful conversations about a person’s individual needs and wishes at time(s) that are appropriate for the person’s needs. It is not a stand-alone activity or tick box exercise. Its importance is in how the results of the HNA are used to reach agreement about ongoing care and support, and thus generate a Personalised Care and Support Plan (see metric LWBC006 and LWBC007) and then for action to be taken to meet identified needs.</p> <p>The rationale for using pathway time points is because they are already part of the COSD data description for Holistic Needs Assessments (HNA) and it is necessary to match whether HNA and Personalised Care and Support Plan have been done together to assess whether an HNA has led to a care plan (metric LWBC007) as per the original concept of the ‘Recovery Package’</p> <p>The rationale for focusing on diagnosis (LWBC004A), start of treatment (LWBC004B), and end of treatment (LWBC004C) is because this is the period of the cancer pathway which is having the most focus in the Cancer Alliances with respect to roll out of HNA and Personalised Care and Support Planning, and it simplifies the production of metric data.</p> <p>The grouping together of the remaining COSD timepoints in LWBC004D of ‘During Treatment’, ‘Diagnosis of Recurrence’, ‘Transition to Palliative Care’ and ‘Other’ does not lessen the importance of conducting HNAs and Personalised Care and Support Planning at these parts, or any other part, of a person’s cancer pathway, if that is what a person needs and agrees to.</p>
Definition	<p>The number of-completed HNAs recorded at cancer diagnosis, treatment and other pathway time points; (date of HNA and pathway time points are defined in the Cancer Outcomes and Services Dataset (COSD)</p> <p><a href="http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd">http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd</a>            CR3140 HOLISTIC NEEDS ASSESSMENT COMPLETED DATE            CR3150 HOLISTIC NEEDS ASSESSMENT POINT OF PATHWAY.</p> <p>These data items changed from ‘optional’ to ‘required’ from April 2018</p>

<b>Draft metric LWBC004 for Holistic Needs Assessment</b>	
	<p><a href="https://digital.nhs.uk/binaries/content/assets/legacy/pdf/8/j/1521742016change-request.pdf">https://digital.nhs.uk/binaries/content/assets/legacy/pdf/8/j/1521742016change-request.pdf</a> See page 24 of the linked document for the HNA change details.</p> <p>To be broken down by individual tumour site.</p> <p><b>Important note:</b> The pathway time points in COSD are not meant to imply that it is a requirement for an HNA to be done at each time point. The COSD time points are simply to enable data to be captured about when (approximately) in the patient pathway an HNA has occurred.</p> <p>HNAs and the accompanying Personalised Care and Support Plans (PCSP) should be shared with other professionals involved in the care of the person, for example a CNS-led HNA/PCSP might be shared with the radiotherapy team and the GP.</p>
Data source	<p>NHS Trusts</p> <p>N.B. NHS England and Public Health England are working towards providing HNA data from COSD, through normal Cancer statistics reporting routes (Cancerstats2<sup>12</sup>) during 2019/2020.</p>
Indicator production	To be decided locally.
Definition of numerator	<p>Number of HNAs completed at the following pathway points</p> <ul style="list-style-type: none"> <li>A. Initial cancer diagnosis</li> <li>B. Start of treatment</li> <li>C. End of treatment</li> <li>D. Other (total of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions)</li> </ul> <p>All of the above should be provided by tumour type.</p>
Source of numerator	As recorded in trusts' systems for COSD purposes.
Definition of denominator	There is no denominator as the only figure required is the number of HNAs.
Source of denominator	There is no denominator.
Methodology	<p><b>LWBC004A</b> The number of completed HNAs at <b>initial cancer diagnosis</b> recorded for the purposes of the COSD dataset.</p> <p><b>LWBC004B</b> The number of completed HNAs at <b>start of treatment</b> recorded for the purposes of the COSD dataset.</p> <p><b>LWBC004C</b> The number of completed HNAs at <b>end of treatment</b> recorded for the purposes of the COSD dataset.</p>

<sup>12</sup> <https://cancerstats.ndrs.nhs.uk/>

<b>Draft metric LWBC004 for Holistic Needs Assessment</b>	
	<p><b>LWBC004D</b> The number of completed HNAs at <b>other pathway time points</b>, namely 'during treatment', 'diagnosis of recurrence', 'transition to palliative care' or 'at an 'other' pathway time point (as recorded for the purposes of the COSD dataset).</p> <p><b>LWBC004T</b> Total of LWBC004A, LWBC004B, LWBC004C and LWBC004D.</p> <p>All of the above should be provided by tumour type.</p>
Data quality	<p>To be determined.</p> <p>Trusts that code all the HNA activity to D 'Other' pathway time point should aim to improve data accuracy and quality.</p> <p>Data quality issues may arise due to:</p> <ul style="list-style-type: none"> <li>• Inability of Trust system to submit HNA data to PHE</li> <li>• Incomplete collection of HNA activity data for COSD purposes</li> <li>• Mis-coding of the pathway time point at which the HNA took place (e.g. a trust might code all of its HNA activity to a default timepoint such as 'during treatment' or 'other').</li> <li>•</li> </ul>
Unit	Number
Year type	Financial
Frequency and data lag	Quarterly. Data lag to be determined.
Interpretation	<p>The figures are a count of number of HNAs carried out, so that over time, progress can be shown in the overall use of HNA at key points in the pathway in a way that is appropriate for each tumour type, without any judgement on whether high coverage should be achieved at any particular pathway point.</p> <p>Numbers will vary depending on:</p> <ul style="list-style-type: none"> <li>• Number of people diagnosed</li> <li>• Availability of staff to conduct HNAs and personalised care and support planning</li> <li>• Needs of people, which differ by cancer type etc.</li> <li>• Whether HNAs and personalised care and support planning have been formally implemented in an MDT.</li> </ul> <p>The metric is intended to provide information to support wider roll-out of HNA and Personalised Care and Support Planning locally, for example:</p> <ul style="list-style-type: none"> <li>• Which teams are using HNAs, and if the number of HNAs appears adequate</li> <li>• Whether over time the numbers are going up/down or staying the same</li> <li>• The points in the pathway that teams are more likely to conduct HNAs</li> </ul> <p>However, this metric is not designed to be used as a benchmark between trusts.</p> <p>The HNA figures for a time period can be compared to the number of people who have had first definitive treatment in the same time period (e.g. LWBC005).</p>

<b>Draft metric LWBC004 for Holistic Needs Assessment</b>	
	<p>HNA activity should never be looked at in isolation from Personalised Care and Support Plan activity, therefore LWBC004, LWBC005, LWBC006 and LWBC007 should always be reported and interpreted together.</p> <p>There are many reasons why HNA figures may be skewed, for example:</p> <ul style="list-style-type: none"> <li>• People may be offered an HNA but may refuse;</li> <li>• People may be diagnosed in an emergency or enter treatment so quickly that there is no time for an HNA;</li> <li>• People may have multiple HNAs in a fairly short space of time, if their needs change rapidly.</li> <li>• Some IT systems allow people to complete an HNA form online at home or on a mobile device as often as they choose;</li> <li>• There may be 'gaming' (e.g. professionals may conduct HNAs when it is not appropriate to do so, just to bump up numbers);</li> <li>• Some organisations see people at diagnosis but not for treatment;</li> <li>• Some community and primary care organisations conduct HNAs, but this data is not captured for COSD.</li> </ul>
Further information	<p>HNA remains a fundamental component of the personalisation of cancer care, and should be very widely conducted as the basis for meaningful conversations about a person's individual needs and wishes. Its importance is therefore in how the results of the HNA are used to reach agreement about ongoing care and support, and thus generate a Personalised Care and Support Plan (see metric LWBC006 and LWBC007) and then for action to be taken to meet identified needs.</p> <p>There should be future work to develop quality measures, including patient feedback, in order to keep improving how HNAs contribute to personalised care from cancer diagnosis onwards. Macmillan is working on this.</p> <p>There had been previous work in trusts to collect HNAs done within 31 days of diagnosis and within 6 weeks of end of treatment. This time frame is not being applied within this standard definition but there could be local recommendation re this or another time frame depending on local post-treatment follow up protocols.</p>
References	<p><u>Definition of Holistic Needs Assessment and Personalised Care and Support Planning</u></p> <p>Holistic Needs Assessment and Personalised Care and Support Planning together create a shared understanding between a person and their team, identifying a person's physical, practical, emotional, lifestyle, spiritual and social needs to ensure these are met in a timely and appropriate way.</p> <p>As described in Chapter 7 of the Independent Cancer Taskforce report :  <i>"[a recovery package includes] a holistic needs assessment and a written individualised care and support plan at key points across the pathway. The patient should agree with and own this plan which should be shared with their GP or other designated local healthcare professional. It should take in to account social circumstances, mental health needs, and any co-morbidities."</i></p>

**Draft metric LWBC004 for Holistic Needs Assessment**

Personalised Care and Support Planning is defined by NHS England: <https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/> (accessed 25 June 2019) and work is ongoing to refine this further.

Resources available from Macmillan Cancer Support:

Recovery Package webpage <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package> (accessed 25 June 2019)

including:

- Holistic Needs Assessment Care and Support Planning (Macmillan Cancer Support 2016) <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774> (accessed 25 June 2019)
- Domain 1 of A Competency Framework for Nurses – Caring for Patients Living with and beyond Cancer (Macmillan Cancer Support 2014) [https://www.macmillan.org.uk/documents/aboutus/health\\_professionals/competence-framework-for-nurses.pdf](https://www.macmillan.org.uk/documents/aboutus/health_professionals/competence-framework-for-nurses.pdf) (accessed 25 June 2019)
- Competence Clusters 1 and 2 of The Macmillan Allied Health Professions Competence Framework for those working with people affected by cancer (Macmillan Cancer Support 2017) [https://www.macmillan.org.uk/images/allied-health-professions-framework\\_tcm9-314735.pdf](https://www.macmillan.org.uk/images/allied-health-professions-framework_tcm9-314735.pdf) (accessed 25 June 2019)

Cancer Outcomes and Services Dataset (COSD)

The National Cancer Registration and Analysis Service (NCRAS) Cancer Outcomes and Services Dataset (COSD) v8.0 downloads [http://www.ncin.org.uk/collecting\\_and\\_using\\_data/data\\_collection/cosd\\_downloads\\_v8](http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v8)

COSD data handbook excerpt:

**HOLISTIC NEEDS ASSESSMENT COMPLETED DATE:** The date a Holistic Needs Assessment (HNA) is completed. Every HNA should be recorded.

**HOLISTIC NEEDS ASSESSMENT POINT OF PATHWAY:** The point in the patient pathway when a Holistic Needs Assessment (HNA) is completed.

01	Initial cancer diagnosis	02	Start of treatment
03	During treatment	04	End of treatment
05	Diagnosis of recurrence	06	Transition to palliative care
98	Other		

<b>Draft metric LWBC005 for 'Timely' Holistic Needs Assessment</b>	
Metric number	LWBC005
Metric short name	Timely Holistic Needs Assessments for people living with and beyond by cancer
Metric full name	The proportion of people who have at least one completed HNA carried out within 31 days of decision to treat for 1 <sup>st</sup> cancer treatment.
Rationale	<p>The <i>NHS England Long Term Plan</i><sup>13</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transform follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing information and support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions;  <i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p>The interventions to support personalisation of care (formerly known as Recovery Package) will be delivered in line with the NHS Comprehensive Model for Personalised Care<sup>14</sup>.</p> <p>The NHS England 2019/20 planning guidance does not specifically mention Holistic Needs Assessments, but the Cancer Programme team guidance to Cancer Alliances states the delivery requirement:  <i>“From diagnosis, all breast/colorectal/prostate cancer patients (including secondary cancer) to have access to personalised care, including <u>needs assessment</u>, a care plan and health and wellbeing information and support”</i> and an additional requirement if funding allows:</p>

<sup>13</sup> <https://www.england.nhs.uk/long-term-plan/>

<sup>14</sup> <https://www.england.nhs.uk/personalisedcare/>

<b>Draft metric LWBC005 for 'Timely' Holistic Needs Assessment</b>	
	<p><i>“Make the following available to patients with cancer types other than breast, prostate and colorectal: <u>Holistic needs assessment</u>, personalised care and support plan, end of treatment summary and health and wellbeing information and support.”</i></p> <p>Improving cancer care from diagnosis was one of the key ambitions in the report, <i>Achieving world-class cancer outcomes: a strategy for England 2015-2020</i>, published by the Independent Cancer Taskforce in July 2015. The Taskforce recommended that NHS England should accelerate the commissioning of services for people living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the 'Recovery Package' by 2020, [including] <u>a holistic needs assessment</u> and a written individualised care and support plan at key points across the pathway.</p> <p>HNA therefore remains a fundamental component of the personalisation of cancer care, and should be very widely conducted as the basis for meaningful conversations about a person's individual needs and wishes at time(s) that are appropriate for the person's needs. It is not a stand-alone activity or tick box exercise. Its importance is in how the results of the HNA are used to reach agreement about ongoing care and support, and thus generate a Personalised Care and Support Plan (see metric LWBC006 and LWBC007) and then for action to be taken to meet identified needs.</p> <p>The rationale for using pathway time points is because they are already part of the COSD data description for Holistic Needs Assessments (HNA) and it is necessary to match whether HNA and Personalised Care and Support Plan have been done together to assess whether an HNA has led to a care plan (metric LWBC007) as per the original concept of the 'Recovery Package'</p> <p>The rationale for focusing on diagnosis (LWBC004A), start of treatment (LWBC004B), and end of treatment (LWBC004C) is because this is the period of the cancer pathway which is having the most focus in the Cancer Alliances with respect to roll out of HNA and Personalised Care and Support Planning, and it simplifies the production of metric data.</p> <p>The grouping together of the remaining COSD timepoints in LWBC004D of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' does not lessen the importance of conducting HNAs and Personalised Care and Support Planning at these parts, or any other part, of a person's cancer pathway, if that is what a person needs and agrees to.</p>
Definition	The proportion of people who have a diagnosis of any cancer who have at least one completed HNA recorded within 31 days of decision to treat for 1 <sup>st</sup> cancer treatment.
Data source	NHS Trusts

<b>Draft metric LWBC005 for 'Timely' Holistic Needs Assessment</b>	
Indicator production	To be agreed locally
Definition of numerator	<p>Number of people who have at least one completed HNA carried out within 31 days of decision to treat for 1<sup>st</sup> cancer treatment <u>plus</u> the number of people who have at least one completed HNA before the decision to treat.</p> <p>This should be split by tumour type.</p>
Source of numerator	As recorded in trusts' systems for COSD purposes.
Definition of denominator	The number of 1st treatments within Cancer Waiting Times dataset. This should be provided by tumour type to match the numerator.
Source of denominator	National Cancer Waiting Times System, sourced by Cancer Alliances locally
Methodology	The number of people who have a diagnosis of any cancer who have at least one completed HNA within 31 days of decision to treat for 1 <sup>st</sup> treatment, divided by 1st treatments recorded in Cancer Waiting Times.
Data quality	To be determined
Unit	Percentage
Year type	Financial
Frequency and data lag	Quarterly. Data lag to be determined.
Interpretation	<p>The higher percentage, the better.</p> <p>This metric is a composite figure designed to indicate the promptness of an HNA being carried out for a person following initial diagnosis, regardless of what time point in the pathway this is done. This allows (for example) for the counting of an HNA done at the 'after treatment' time point for people whose cancer diagnosis has been made as an outcome of emergency surgery. Some people may have more than one HNA in the 31 days but these people should be counted only once.</p> <p>It should also be noted that HNAs may not be undertaken at the same trust who provides 1<sup>st</sup> treatment for cancer, which means the LWBC005 should be interpreted with caution at trust level. At a system level however, the data at tumour level will reflect rollout of HNA for that population.</p> <p>HNA activity should never be looked at in isolation from Personalised Care and Support Plan activity, therefore LWBC004, LWBC005, LWBC006 and LWBC007 should always be reported and interpreted together.</p>
Further information	HNA remains a fundamental component of the personalisation of cancer care, and should be very widely conducted as the basis for meaningful conversations about a person's individual needs and wishes. Its importance is therefore in how the results of the HNA are used to reach agreement about ongoing care and support, and thus

<b>Draft metric LWBC005 for ‘Timely’ Holistic Needs Assessment</b>	
	generate a Personalised Care and Support Plan (see metric LWBC006 and LWBC007) and then for action to be taken to meet identified needs.
References	<p><u><a href="#">Definition of Holistic Needs Assessment and Personalised Care and Support Planning</a></u></p> <p>Holistic Needs Assessment and Personalised Care and Support Planning together create a shared understanding between a person and their team, identifying a person’s physical, practical, emotional, lifestyle, spiritual and social needs to ensure these are met in a timely and appropriate way.</p> <p>As described in Chapter 7 of the Independent Cancer Taskforce report: <i>“[a recovery package includes] a holistic needs assessment and a written individualised care and support plan at key points across the pathway. The patient should agree with and own this plan which should be shared with their GP or other designated local healthcare professional. It should take in to account social circumstances, mental health needs, and any co-morbidities.”</i></p> <p>Personalised Care and Support Planning is defined by NHS England: <a href="https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/">https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/</a> (accessed 25 June 2019) and work is ongoing to refine this further.</p> <p><u><a href="#">Resources available from Macmillan Cancer Support:</a></u></p> <p>Recovery Package webpage <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package</a> (accessed 5 April 2019)</p> <p>including:</p> <ul style="list-style-type: none"> <li>• Holistic Needs Assessment Care and Support Planning (Macmillan Cancer Support 2016) <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774</a> (accessed 25 June 2019)</li> <li>• Domain 1 of A Competency Framework for Nurses – Caring for Patients Living with and beyond Cancer (Macmillan Cancer Support 2014) <a href="https://www.macmillan.org.uk/documents/aboutus/health_professionals/competence-framework-for-nurses.pdf">https://www.macmillan.org.uk/documents/aboutus/health_professionals/competence-framework-for-nurses.pdf</a> (accessed 25 June 2019)</li> </ul> <p>Competence Clusters 1 and 2 of The Macmillan Allied Health Professions Competence Framework for those working with people affected by cancer (Macmillan Cancer Support 2017)</p>

**Draft metric LWBC005 for 'Timely' Holistic Needs Assessment**

[https://www.macmillan.org.uk/images/allied-health-professions-framework\\_tcm9-314735.pdf](https://www.macmillan.org.uk/images/allied-health-professions-framework_tcm9-314735.pdf) (accessed 25 May 2019)

Cancer Outcomes and Services Dataset (COSD)

The National Cancer Registration and Analysis Service (NCRAS)  
Cancer Outcomes and Services Dataset (COSD) v8.0 downloads  
[http://www.ncin.org.uk/collecting\\_and\\_using\\_data/data\\_collection/cosd\\_downloads\\_v8](http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v8)

COSD data handbook excerpt:

**HOLISTIC NEEDS ASSESSMENT COMPLETED DATE:** The date a Holistic Needs Assessment (HNA) is completed. Every HNA should be recorded.

**HOLISTIC NEEDS ASSESSMENT POINT OF PATHWAY:** The point in the patient pathway when a Holistic Needs Assessment (HNA) is completed.

- 01 Initial cancer diagnosis
- 02 Start of treatment
- 03 During treatment
- 04 End of treatment
- 05 Diagnosis of recurrence
- 06 Transition to palliative care
- 98 Other

<b>Draft metric LWBC006 for Personalised Care and Support Plans</b>	
Metric number	LWBC006A, LWBC006B, LWBC006C, LWBC006D, LWBC006T
Metric short name	Personalised Care and Support Plans for people living with and beyond cancer
Metric full name	The number of completed Personalised Care and Support Plans at cancer diagnosis, treatment and other time points: A. Initial cancer diagnosis B. Start of treatment C. End of treatment D. Other (total of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions) T. Total of A + B+ C + D
Rationale	<p>The <i>NHS England Long Term Plan</i><sup>15</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transform follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions;  <i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p>The interventions to support personalisation of care (formerly known as Recovery Package) will be delivered in line with the NHS Comprehensive Model for Personalised Care<sup>16</sup>. This model includes Personalised Care and Support Planning as one of its six core components. The implementation plan<sup>17</sup> for the NHS Comprehensive Model for Personalised Care commits by 2023/24 that 750,000 people will have Personalised Care and Support Plans to manage their long term health condition.</p>

<sup>15</sup> <https://www.england.nhs.uk/long-term-plan/>

<sup>16</sup> <https://www.england.nhs.uk/personalisedcare/>

<sup>17</sup> <https://www.england.nhs.uk/personalisedcare/upc/comprehensive-model/>

	<p>The NHS England 2019/20 planning guidance for cancer does not specifically mention Personalised Care and Support Plans but the Cancer Programme team guidance to Cancer Alliances states the delivery requirement: <i>“From diagnosis, all breast/colorectal/prostate cancer patients (including secondary cancer) to have access to personalised care, including needs assessment, <u>a care plan</u> and health and wellbeing information and support”</i> and an additional requirement if funding allows: <i>“Make the following available to patients with cancer types other than breast, prostate and colorectal: <u>Holistic needs assessment, personalised care and support plan, end of treatment summary and health and wellbeing information and support.</u>”</i></p> <p>Improving cancer care from diagnosis was one of the key ambitions in the report, <i>Achieving world-class cancer outcomes: a strategy for England 2015-2020</i>, published by the Independent Cancer Taskforce in July 2015. The Taskforce recommended that NHS England should accelerate the commissioning of services for people living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the ‘Recovery Package’ by 2020, [including] a holistic needs assessment and a <u>written individualised care and support plan</u> at key points across the pathway.</p> <p>Personalised Care and Support Planning therefore remains a fundamental component of the personalisation of cancer care, and should be very widely offered, based on an HNA, as the basis for meaningful actions to be taken to meet a person’s individual needs and wishes at time(s) that are appropriate for the person’s needs. It is not a stand-alone activity or tick box exercise. The person living with or beyond cancer should co-produce, agree with and own this plan which should be shared (with permission) with their GP and/or other designated local healthcare professionals. It should take in to account social circumstances, mental health needs, and any co-morbidities.</p> <p>The rationale for using pathway time points is because they are already part of the COSD data description for Holistic Needs Assessments (HNA) and it is necessary to match whether HNA and Personalised Care and Support Plan have been done together to assess whether an HNA has led to a plan (unless there is an agreed reason not to develop a plan) as per the original concept of the Recovery Package (metric LWBC007).</p> <p>The rationale for focusing on diagnosis (LWBC006A), start of treatment (LWBC006B) and end of treatment (LWBC006C) is because this is the period of the cancer pathway which is having the most focus in the Cancer Alliances with respect to roll out of HNA and Personalised Care and Support Planning, and it simplifies the production of metric data.</p> <p>The grouping together of the COSD timepoints of ‘During Treatment’, ‘Diagnosis of Recurrence’, ‘Transition to Palliative Care’ and ‘Other’ (LWBC006D) does not lessen the importance of conducting HNAs and Personalised Care and Support Planning at these parts, or any other part, of a person’s cancer pathway, if that is what a person needs and agrees to.</p>
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	Its importance is in whether a Personalised Care and Support Plan is developed in order to take appropriate action to be taken to meet identified needs.
Definition	<p>The total of: The number of completed Personalised Care and Support Plans  plus  the number of times it is agreed by the person with their professional that, following an HNA, a Personalised Care and Support Plan is not required at that time (i.e. care planning is offered but is declined or unable to happen),  at the following pathway points;</p> <ul style="list-style-type: none"> <li>A. Initial cancer diagnosis</li> <li>B. Start of treatment</li> <li>C. End of treatment</li> <li>D. Other (total of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions)</li> </ul> <p>All of the above should be provided by tumour type.</p> <p><u>Important note:</u> The pathway time points (from COSD) are not meant to imply that it is a requirement for a Personalised Care and Support Plan to be done at each time point. The COSD time points are simply to enable data to be captured about when (approximately) in the patient pathway an HNA has occurred.</p> <p>HNAs and the accompanying Personalised Care and Support Plans (PCSP) should be shared with other professionals involved in the care of the person, for example a CNS-led HNA/PCSP might be shared with the radiotherapy team and the GP.</p>
Data source	NHS Trusts
Indicator production	To be decided locally.
Definition of numerator	<p>The total of: The number of completed Personalised Care and Support Plans  plus the number of times it is agreed by the person with their professional that, following an HNA, a Personalised Care and Support Plan is not required at that time; at the following pathway points;</p> <ul style="list-style-type: none"> <li>A. Initial cancer diagnosis</li> <li>B. Start of treatment</li> <li>C. End of treatment</li> <li>D. Other (total of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions)</li> </ul> <p>All of the above should be provided by tumour type.</p>
Source of numerator	As recorded in trusts' systems
Definition of denominator	There is no denominator

Source of denominator	There is no denominator
Methodology	<p><b>LWBC006A</b> The number of completed Personalised Care and Support Plans at <b>initial cancer diagnosis</b> recorded for the purposes of the COSD dataset.</p> <p><b>LWBC006B</b> The number of completed Personalised Care and Support Plans at <b>start of treatment</b> recorded for the purposes of the COSD dataset.</p> <p><b>LWBC006C</b> The number of completed Personalised Care and Support Plans at <b>end of treatment</b> recorded for the purposes of the COSD dataset.</p> <p><b>LWBC006D</b> The number of completed Personalised Care and Support Plans at <b>other pathway time points</b>, namely ‘during treatment’ , ‘diagnosis of recurrence’ , ‘transition to palliative care’ or ‘at an ‘other’ pathway time point ( as recorded for the purposes of the COSD dataset).</p> <p><b>LWBC006T</b> Total of LWBC006A, LWBC006B, LWBC006C and LWBC006D.</p> <p>All of the above should be provided by tumour type.</p>
Data quality	Data quality issues may arise due to mis-coding of the pathway time point at which the PCSP took place (e.g. a trust might code all of its PCSP activity to a default timepoint such as ‘during treatment’ or ‘other’).
Unit	Percentage
Year type	Financial
Frequency and data lag	Quarterly. Data lag to be determined.
Interpretation	<p>Interpretation of the metric should be made with care as there is no requirement (yet) for the number of Personalised Care and Support Plans (PCSPs) to reach any particular target level.</p> <p>Personalised Care and Support Plan activity should never be looked at in isolation from Holistic Needs Assessment activity, therefore LWBC004, LWBC005, LWBC006 and LWBC007 should always be reported and interpreted together.</p> <p>The figures are a count of number of PCSPs carried out, so that over time, progress can be shown in the overall use of personalised care and support planning at key points in the pathway in a way that is appropriate for each tumour type, without any judgement on whether high coverage should be achieved at any particular pathway point.</p> <p>Numbers will vary depending on:</p> <ul style="list-style-type: none"> <li>• Number of people diagnosed</li> <li>• Availability of staff to conduct HNAs and personalised care and support planning</li> <li>• Needs of people, which differ by cancer type etc.</li> <li>• Whether HNAs and personalised care and support planning have been implemented in an MDT.</li> </ul>

	<p>The metric is intended to provide information to support wider roll-out of HNA and personalised care and support planning locally, for example:</p> <ul style="list-style-type: none"> <li>• Which teams are using personalised care and support planning, and if the number of plans appears adequate</li> <li>• Whether over time the numbers are going up/down or staying the same</li> <li>• The points in the pathway that teams are more likely to agree PCSPs.</li> </ul> <p>However, this metric is not designed to be used as a benchmark between trusts.</p> <p>The PCSP figures for a time period can be compared to the number of people who have had first definitive treatment in the same time period – this is an optional analysis that organisations may wish to conduct.</p> <p>HNA activity should never be looked at in isolation from Personalised Care and Support Plan activity, therefore LWBC004, LWBC005, LWBC006 and LWBC007 should always be reported and interpreted together.</p>
Further information	<p>Personalised Care and Support Planning remains a fundamental component of the personalisation of cancer care, and should be very widely carried out except in circumstances where there is a shared decision that a person does not have concerns or problems that would warrant a care plan document being created.</p> <p>Personalised Care and Support Planning should normally be based on a Holistic Needs Assessment (HNA) – see metric LWBC004 and LWBC005.</p>
References	<p><u><a href="#">Definition of Holistic Needs Assessment and Personalised Care and Support Planning</a></u></p> <p>Holistic Needs Assessment and Personalised Care and Support Planning together create a shared understanding between a person and their team, identifying a person’s physical, practical, emotional, lifestyle, spiritual and social needs to ensure these are met in a timely and appropriate way.</p> <p>As described in Chapter 7 of the Independent Cancer Taskforce report: <i>“[a recovery package includes] a holistic needs assessment and a written individualised care and support plan at key points across the pathway. The patient should agree with and own this plan which should be shared with their GP or other designated local healthcare professional. It should take in to account social circumstances, mental health needs, and any co-morbidities.”</i></p> <p>Personalised Care and Support Planning is defined by NHS England: <a href="https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/">https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/</a> (accessed 25 June 2019) and work is ongoing to refine this further.</p>

	<p><u>Resources available from Macmillan Cancer Support:</u></p> <p>Recovery Package webpage <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package</a> (accessed 25 June 2019)</p> <p>including:</p> <ul style="list-style-type: none"><li>• Holistic Needs Assessment Care and Support Planning (Macmillan Cancer Support 2016) <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#29777">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#29777</a> (accessed 25 June 2019)</li><li>• Domain 1 of A Competency Framework for Nurses – Caring for Patients Living with and beyond Cancer (Macmillan Cancer Support 2014) <a href="https://www.macmillan.org.uk/documents/aboutus/health_professionals/competence-framework-for-nurses.pdf">https://www.macmillan.org.uk/documents/aboutus/health_professionals/competence-framework-for-nurses.pdf</a> (accessed 25 June 2019)</li><li>• Competence Clusters 1 and 2 of The Macmillan Allied Health Professions Competence Framework for those working with people affected by cancer (Macmillan Cancer Support 2017) <a href="https://www.macmillan.org.uk/images/allied-health-professions-framework_tcm9-314735.pdf">https://www.macmillan.org.uk/images/allied-health-professions-framework_tcm9-314735.pdf</a> (accessed 25 June 2019)</li></ul>
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<b>Draft Metric LWBC007 for Holistic Needs Assessments leading to Personalised Care and Support Plans</b>	
Metric number	LWBC007A, LWBC007B, LWBC007C, LWBC007D, LWBC007T
Metric short name	Holistic Needs Assessments leading to Personalised Care and Support Plans for people living with and beyond cancer
Metric full name	The percentage of Holistic Needs Assessments that lead to completed Personalised Care and Support Plans for people affected by cancer at different points in the cancer pathway: A. Initial cancer diagnosis B. Start of treatment C. End of treatment D. Other (total of 'During Treatment, 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions) T. Total of A + B+ C + D
Rationale	<p>The <i>NHS England Long Term Plan</i><sup>18</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transform follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions;  <i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p>The interventions to support personalisation of care (formerly known as Recovery Package) will be delivered in line with the NHS Comprehensive Model for Personalised Care<sup>19</sup>. This model includes Personalised Care and Support Planning as one of its six core components. The implementation plan<sup>20</sup> for the NHS Comprehensive Model for</p>

<sup>18</sup> <https://www.england.nhs.uk/long-term-plan/>

<sup>19</sup> <https://www.england.nhs.uk/personalisedcare/>

<sup>20</sup> <https://www.england.nhs.uk/personalisedcare/upc/comprehensive-model/>

**Draft Metric LWBC007 for Holistic Needs Assessments leading to Personalised Care and Support Plans**

Personalised Care commits by 2023/24 that 750,000 people will have Personalised Care and Support Plans to manage their long term health condition.

The NHS England 2019/20 planning guidance for cancer does not specifically mention Personalised Care and Support Plans but the Cancer Programme team guidance to Cancer Alliances states the delivery requirement:

*“From diagnosis, all breast/colorectal/prostate cancer patients (including secondary cancer) to have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support”*

and an additional requirement if funding allows:

*“Make the following available to patients with cancer types other than breast, prostate and colorectal: Holistic needs assessment, personalised care and support plan, end of treatment summary and health and wellbeing information and support.”*

Improving cancer care from diagnosis was one of the key ambitions in the report, *Achieving world-class cancer outcomes: a strategy for England 2015-2020*, published by the Independent Cancer Taskforce in July 2015. The Taskforce recommended that NHS England should accelerate the commissioning of services for people living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the ‘Recovery Package’ by 2020, [including] a holistic needs assessment and a written individualised care and support plan at key points across the pathway.

Personalised Care and Support Planning therefore remains a fundamental component of the personalisation of cancer care, and should be very widely offered, based on an HNA, as the basis for meaningful actions to be taken to meet a person’s individual needs and wishes at time(s) that are appropriate for the person’s needs. It is not a stand-alone activity or tick box exercise. The person living with or beyond cancer should co-produce, agree with and own this plan which should be shared (with permission) with their GP and/or other designated local healthcare professionals. It should take in to account social circumstances, mental health needs, and any co-morbidities.

The rationale for using pathway time points is because they are already part of the COSD data description for Holistic Needs Assessments (HNA) and it is necessary to match whether HNA and Personalised Care and Support Plan have been done together to assess whether an HNA has led to a plan (unless there is an agreed reason not to develop a plan) as per the original concept of the Recovery Package (metric LWBC007).

The rationale for focusing on diagnosis (LWBC006A), start of treatment (LWBC006B) and end of treatment (LWBC006C) is because this is the period of the cancer pathway which is having the most focus in the Cancer Alliances with respect to roll out of HNA and Personalised Care and Support Planning, and it simplifies the production of metric data.

<b>Draft Metric LWBC007 for Holistic Needs Assessments leading to Personalised Care and Support Plans</b>	
	<p>The grouping together of the COSD timepoints of 'During Treatment, 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' (LWBC006D) does not lessen the importance of conducting HNAs and Personalised Care and Support Planning at these parts, or any other part, of a person's cancer pathway, if that is what a person needs and agrees to.</p> <p>Its importance is in whether a Personalised Care and Support Plan is developed in order to take appropriate action to be taken to meet identified needs.</p>
Definition	<p>The percentage of Holistic Needs Assessments that lead to completed Personalised Care and Support Plans for people living with and beyond cancer at different points in the cancer pathway:</p> <ul style="list-style-type: none"> <li>A. Initial cancer diagnosis</li> <li>B. Start of treatment</li> <li>C. End of treatment</li> <li>D. Other (total of 'During Treatment, 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions)</li> <li>T. Total of A + B+ C + D</li> </ul> <p>All of the above should be provided by tumour type.</p>
Data source	NHS Trusts
Indicator production	To be decided locally.
Definition of numerator	<p>The total of:                      The number of completed Personalised Care and Support Plans plus the number of times it is agreed by the person with their professional that, following an HNA, a Personalised Care and Support Plan is not required at that time (i.e. care planning is offered but is declined or unable to happen), at different points in the cancer pathway:</p> <ul style="list-style-type: none"> <li>A. Initial cancer diagnosis</li> <li>B. Start of treatment</li> <li>C. End of treatment</li> <li>D. Other (total of 'During Treatment, 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions)</li> <li>T. Total of A + B+ C + D</li> </ul> <p>This should be provided by tumour type</p>
Source of numerator	As recorded in trusts' systems

<b>Draft Metric LWBC007 for Holistic Needs Assessments leading to Personalised Care and Support Plans</b>	
Definition of denominator	The number of Holistic Needs Assessments as per LWBC004A, LWBC004B, LWBC004C, LWBC004D and LWBC004T at different points in the cancer pathway: A. Initial cancer diagnosis B. Start of treatment C. End of treatment D. Other (total of 'During Treatment', 'Diagnosis of Recurrence', 'Transition to Palliative Care' and 'Other' from COSD definitions) T. Total of A + B+ C + D
Source of denominator	As recorded in trusts' systems for COSD purposes
Methodology	The number of completed Personalised Care and Support Plans (including the number of times it is agreed by the person with their professional that, following an HNA, a Personalised Care and Support Plan is not required at that time) divided by the number of Holistic Needs Assessments
Data quality	To be determined
Unit	Percentage
Year type	Financial
Frequency and data lag	Quarterly. Data lag to be determined.
Interpretation	<p>Interpretation of the metric should be made with care as there is no requirement (yet) for the percentage of HNAs that result in a Personalised Care and Support Plan to reach any particular target level. Suggestions are in the range 50 to 70%.</p> <p>The figures will show if over time, progress can be shown in increasing the conversion rate of HNA to PCSP in a way that is appropriate for each tumour type, at different pathway points.</p> <p>Percentages will vary depending on data from metrics LWBC004 and LWBC006. Zero or small numbers of HNAs or PCSPs will skew LWBC007.</p> <p>The metric is intended to provide information to support wider roll-out of HNA and Personalised Care and Support Planning locally, for example:</p> <ul style="list-style-type: none"> <li>• Which teams have higher proportions of HNAs being converted to PCSPs</li> <li>• Whether over time the figures are going up/down or staying the same</li> <li>• The points in the pathway that teams are more likely to successfully have a PCSP resulting from an HNA</li> </ul> <p>This metric could be used as a benchmark between trusts.</p>

<b>Draft Metric LWBC007 for Holistic Needs Assessments leading to Personalised Care and Support Plans</b>	
	HNA activity should never be looked at in isolation from Personalised Care and Support Plan activity, therefore LWBC004, LWBC005, LWBC006 and LWBC007 should always be reported and interpreted together.
Further information	<p>Personalised Care and Support Planning remains a fundamental component of the personalisation of cancer care, and should be very widely carried out except in circumstances where a person does not have concerns or problems that would warrant a care plan document being created.</p> <p>Personalised Care and Support Planning should be based on a Holistic Needs Assessment (HNA) – see metric LWBC004 and LWBC005.</p>
References	<p><u>Definition of Holistic Needs Assessment and Personalised Care and Support Planning</u></p> <p>Holistic Needs Assessment and Personalised Care and Support Planning together create a shared understanding between a person and their team, identifying a person’s physical, practical, emotional, lifestyle, spiritual and social needs to ensure these are met in a timely and appropriate way.</p> <p>As described in Chapter 7 of the Independent Cancer Taskforce report: <i>“[a recovery package includes] a holistic needs assessment and a written individualised care and support plan at key points across the pathway. The patient should agree with and own this plan which should be shared with their GP or other designated local healthcare professional. It should take in to account social circumstances, mental health needs, and any co-morbidities.”</i></p> <p>Personalised Care and Support Planning is defined by NHS England: <a href="https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/">https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/</a> (accessed 25 June 2019) and work is ongoing to refine this further.</p> <p><u>Resources available from Macmillan Cancer Support:</u></p> <p>Recovery Package webpage <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package</a> (accessed 25 June 2019)</p> <p>including:</p> <ul style="list-style-type: none"> <li>• Holistic Needs Assessment Care and Support Planning (Macmillan Cancer Support 2016) <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774</a> (accessed 25 June 2019)</li> </ul>

**Draft Metric LWBC007 for Holistic Needs Assessments leading to Personalised Care and Support Plans**

- Domain 1 of A Competency Framework for Nurses – Caring for Patients Living with and beyond Cancer (Macmillan Cancer Support 2014)  
[https://www.macmillan.org.uk/documents/aboutus/health\\_professionals/competence-framework-for-nurses.pdf](https://www.macmillan.org.uk/documents/aboutus/health_professionals/competence-framework-for-nurses.pdf) (accessed 25 June 2019)
- Competence Clusters 1 and 2 of The Macmillan Allied Health Professions Competence Framework for those working with people affected by cancer (Macmillan Cancer Support 2017)  
[https://www.macmillan.org.uk/images/allied-health-professions-framework\\_tcm9-314735.pdf](https://www.macmillan.org.uk/images/allied-health-professions-framework_tcm9-314735.pdf) (accessed 25 June 2019)

<b>Draft metric LWBC008 for End of Treatment Summaries</b>	
Metric number	LWBC008
Metric short name	End of Treatment Summaries for people living with and beyond cancer
Metric full name	The percentage of people treated for cancer with a completed End of Treatment Summary
Rationale	<p>The <i>NHS England Long Term Plan</i><sup>21</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transform follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions;  <i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p>The interventions to support personalisation of care (formerly known as Recovery Package) will be delivered in line with the NHS Comprehensive Model for Personalised Care<sup>22</sup>.</p> <p>The NHS England 2019/20 planning guidance for cancer does not specifically mention End of Treatment Summaries but the Cancer Programme team guidance to Cancer Alliances states the delivery requirement:  <i>“From diagnosis, all breast/colorectal/prostate cancer patients (including secondary cancer) to have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support”</i>  and an additional requirement if funding allows:  <i>“Make the following available to patients with cancer types other than breast, prostate and colorectal: Holistic needs assessment, personalised</i></p>

<sup>21</sup> <https://www.england.nhs.uk/long-term-plan/>

<sup>22</sup> <https://www.england.nhs.uk/personalisedcare/>

<b>Draft metric LWBC008 for End of Treatment Summaries</b>	
	<p><i>care and support plan, <u>end of treatment summary</u> and health and wellbeing information and support.”</i></p> <p>Improving cancer care from diagnosis was one of the key ambitions in the report, <i>Achieving world-class cancer outcomes: a strategy for England 2015-2020</i>, published by the Independent Cancer Taskforce in July 2015. The Taskforce recommended that NHS England should accelerate the commissioning of services for people living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the ‘Recovery Package’ by 2020, [including] “<u>a treatment summary completed at the end of every phase of acute treatment, sent to the patient and their GP</u>”.</p> <p>The Taskforce recommended that an End of Treatment Summary should be provided after every phase of acute treatment, (i.e., cancer surgery, chemotherapy, radiotherapy), but during implementation, some teams have decided to produce only one Treatment Summary, after all acute treatments have ended, which may be more appropriate and achievable.</p> <p>As the rationale for End of Treatment Summaries is to improve communication (between all relevant parties – the person living with and beyond cancer, secondary care teams including rehabilitation, primary care team), if this goal is achieved within a clinically appropriate time frame then this is acceptable.</p> <p>For core components, see below.</p>
Definition	The percentage of people who have a diagnosis of any cancer who are provided with an End of Treatment Summary that has been shared with the person and their GP within a clinically appropriate time frame.
Data source	NHS Trusts
Indicator production	To be decided locally.
Definition of numerator	Number of people who have a diagnosis of any cancer who are provided with an End of Treatment Summary that has been shared with the person and their GP within a clinically appropriate time frame.
Source of numerator	Trust data
Definition of denominator	The number of people who have their first definitive treatment for cancer
Source of denominator	National Cancer Waiting Times system
Methodology	The number of people who have an End of Treatment Summary divided by 1 <sup>st</sup> treatments recorded within Cancer Waiting Times dataset
Data quality	To be determined
Unit	Percentage
Year type	Financial

<b>Draft metric LWBC008 for End of Treatment Summaries</b>	
Frequency and data lag	Quarterly. Data lag to be determined.
Interpretation	<p>Interpretation of the metric should be made with care as there is no requirement (yet) for the proportion of people who have End of Treatment Summaries to reach any particular target level.</p> <p>However, the higher the figure, the better. It may be greater than 100% if an End of Treatment Summary is provided after each phase of acute treatment.</p>
Further information	<p>End of Treatment Summaries are a fundamental component of the personalisation of cancer care, and should be produced to agreed trust-level or Cancer Alliance-level templates for each cancer type.</p> <p>They are produced for all people by secondary care 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 the person living with and/or beyond cancer.</p> <p>It supports improved communication so that primary care know how to support the person, for example, by taking action regarding potential cancer recurrence and/or preventing, monitoring for or managing long term consequences of treatment. It helps improve the person's understanding of their condition, their treatment and what they can do to monitor and help themselves.</p> <p>During implementation, some teams have decided to produce only one End of Treatment Summary, i.e. after all acute treatments have ended, which may be more appropriate and achievable. As the rationale for End of Treatment Summaries is to improve communication (between all relevant parties – the person living with and beyond cancer, secondary care teams including rehabilitation, primary care team), if this goal is achieved within a clinically appropriate time frame then this is acceptable.</p> <p>End of Treatment Summaries should be shared electronically with the person and their GP practice, or on paper if electronic means are not available.</p> <p>Core components include (see <a href="#">Macmillan guide</a> for further information)</p> <ul style="list-style-type: none"> <li>• summary of diagnosis and treatment</li> <li>• potential markers of recurrence/secondary cancers and information on what to do in these circumstances</li> <li>• information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years,</li> <li>• key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent.</li> <li>• referrals made to other services, e.g. rehabilitation, mental health care</li> <li>• prompts for GP actions</li> </ul>

<b>Draft metric LWBC008 for End of Treatment Summaries</b>	
	<ul style="list-style-type: none"><li>lifestyle information and advice that the person has been given or signposted to, including details of local support groups and psychosocial support, complementary therapies, returning to work advice etc.</li></ul>
References	<u>End of Treatment Summaries</u>  As described in Chapter 7 of the Independent Cancer Taskforce <sup>23</sup> report : Recommendation 65. (accessed 5 April 2019).
	<u>Resources available from Macmillan Cancer Support</u>  Recovery Package webpage <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package</a> (accessed 25 June 2019) including:  Treatment Summary How To Guide (Macmillan Cancer Support 2016) <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774</a> (accessed 25 June 2019)

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<sup>23</sup> [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<b>Draft metric LWBC009 for Health and Wellbeing Information and Support</b>	
Metric number	LWBC009
Metric short name	Health and Wellbeing Information and Support for people affected by cancer
Metric full name	The proportion of a Cancer Alliance population with a comprehensive health and wellbeing information and support (HWBIS) offer that meets the needs of people affected by cancer (including carers) and increases their ability to manage their own health and wellbeing.
Rationale	<p>The <i>NHS England Long Term Plan</i><sup>24</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transform follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions;  <i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p>The interventions to support personalisation of care (formerly known as Recovery Package) will be delivered in line with the NHS Comprehensive Model for Personalised Care<sup>25</sup>. Thus the emphasis has changed from one-off health and wellbeing clinics/events to a more comprehensive range of ongoing, accessible health and wellbeing information and support from diagnosis onwards.</p> <p>The NHS England 2019/20 planning guidance for cancer does not specifically mention HWBIS but the Cancer Programme team guidance to Cancer Alliances states the delivery requirement:</p>

<sup>24</sup> <https://www.england.nhs.uk/long-term-plan/>

<sup>25</sup> <https://www.england.nhs.uk/personalisedcare/>

**Draft metric LWBC009 for Health and Wellbeing Information and Support**

*“From diagnosis, all breast/colorectal/prostate cancer patients (including secondary cancer) to have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support”*

and an additional requirement if funding allows:

*“Make the following available to patients with cancer types other than breast, prostate and colorectal: Holistic needs assessment, personalised care and support plan, end of treatment summary and health and wellbeing information and support.”*

Improving cancer care from diagnosis was one of the key ambitions in the report, *Achieving world-class cancer outcomes: a strategy for England 2015-2020*, published by the Independent Cancer Taskforce in July 2015. The Taskforce recommended that NHS England should accelerate the commissioning of services for people living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the ‘Recovery Package’ by 2020, [including] *“Access to a patient education and support event, such as a Health and Wellbeing Clinic, to prepare the person for the transition to supported self-management, including advice on healthy lifestyle and physical activity”*.

This metric LWBC009 signals a clear move away from the idea that attendance at one-off post-treatment Health and Wellbeing ‘clinics’ or ‘events’ is the only important aspect of HWBIS for people and their carers. These events and courses are generally very popular but attendance at Health and Wellbeing events is not a good measure of the entirety of HWBIS for people, and also many events are run by charities and therefore data is not able to be captured on NHS systems.

Working on wider footprints (probably at STP level, but in some places either at CCG or Alliance level) allows for wider consideration of all available health and non-health services that could constitute HWBIS – many of which may not be specific to cancer.

In addition, this metric LWBC009 signals:

- the need for HWBIS to be given much higher profile with commissioners, and to be developed in a collaborative way across many partner organisations, taking account of health inequalities and the needs of the population;
- the need for a comprehensive HWBIS offer to be available locally, to underpin the implementation of personalised stratified pathways, other personalised care interventions and support for self-management;
- the need for the HWBIS offer to be integrated into the cancer pathway from diagnosis, not just as a post-treatment activity;
- The need for the HWBIS offer to reflect that cancer and its consequences has become a long-term condition for many people.

<b>Draft metric LWBC009 for Health and Wellbeing Information and Support</b>	
Definition	The proportion of a Cancer Alliance population with a comprehensive, accessible Health and Wellbeing Information and Support offer that meets the needs of people affected by cancer (including carers) from diagnosis onwards and which increases their ability to manage their own health and wellbeing.
Data source	CCGs/STPs
Indicator production	Cancer Alliances
Definition of numerator	<p>Number of CCGs/STPs that have a comprehensive, accessible Health and Wellbeing Information and Support offer that meets the needs of people affected by cancer (including carers) from diagnosis onwards and which increases their ability to manage their own health and wellbeing.</p> <p>The definition of ‘comprehensive Health and Wellbeing Information and Support offer’ is that the CCG/STP has documented and disseminated information on the range of support that is free of charge and accessible (locally and remotely) for all people affected by cancer. To be updated at least annually.</p> <p>All CCGs/STPs should have the Health and Wellbeing Information and Support offer documented as a statement of fact of what is currently available. It is not a development plan or commissioning intentions, although it could be expected to lead to these being produced.</p> <p>The document should be designed to be widely accessible to any person, carer or professional as a way of signposting or (self) referring someone to the support that will meet their holistic needs, and help to improve their and their carers’ health and wellbeing from cancer diagnosis onwards.</p> <p>The document or website describing the Health and Wellbeing Information and Support offer should have the following core components:-</p> <ul style="list-style-type: none"> <li>• Be based on Joint Strategic Needs Assessment of people affected by cancer and/or based on local aggregate Holistic Needs Assessment data, or other data on expressed concerns and needs, where available. This should include how health inequalities for people living with and beyond cancer are being addressed.</li> <li>• Cover what is available through the NHS, local authority, third sector, community organisations, digital support (such as websites, Apps and patient portals) etc. which include both cancer-specific provision and general population provision. It could be based on existing local directories of support for people affected by cancer, such as this one from Leeds <a href="http://flipbooks.leedsth.nhs.uk/LN004113/">http://flipbooks.leedsth.nhs.uk/LN004113/</a> (accessed 25 June</li> </ul>

**Draft metric LWBC009 for Health and Wellbeing Information and Support**

2019).

- Endorsement from the relevant statutory organisations for the population being covered by the document.
- Describe how an individual's health and wellbeing needs should be identified early (and whenever needs change later on) via personalised care and support planning based on holistic needs assessments.
- Describe a range of choice in how the Health and Wellbeing Information and Support offer is delivered, which encourages personalisation and choice for each person's circumstances and needs, and which covers children, young adults, adults and carers.

For example:

- Information in accessible formats that signposts people to a choice of information sources, support organisations and groups;
- Face to face Health and Wellbeing Information and Support events, 'clinics' or courses designed for people affected by cancer, held in hospital or community settings by NHS, community or third sector organisations;
- Peer support buddies, patient support groups and online forums;
- Individual health and wellbeing one-to-one consultation/education/outreach sessions with a clinical nurse specialist or other professional.  
NB in general, a sole one-to-one end of treatment session to support self-managed follow up would not constitute a complete Health and Wellbeing Information and Support offer to an individual as there should be Health and Wellbeing Information and Support from diagnosis;
- Routes for accessing support for
  - emotional, cognitive and mental health issues, including fear of recurrence, depression, memory problems and PTSD;
  - long-term physical consequences of treatment including (but not limited to) difficulties with/due to:
    - mobility
    - lymphoedema
    - bowel

**Draft metric LWBC009 for Health and Wellbeing Information and Support**

- bladder
- sexual activity
- hormones
- bone
- cardiovascular
- fatigue
- pain
- fertility
- eating/speech
- breathing
- hearing
- sight
- neurological problems
- risk of second primary cancers;
  - remaining in, or returning to, work or education;
  - physical activity;
  - smoking cessation;
  - other healthy lifestyle choices;
  - carers and family support;
  - palliative and end of life care.
- Provision of advice and services around education, personal finance, advocacy, housing etc.
- Events or courses provided locally, such as adult education classes.
- Social prescribing.
- Information so that people understand that they are entitled to:
  - personalised care and support planning based on holistic needs assessment,
  - an End of Treatment Summary(s) provided by cancer care teams that includes information and prompts for action by the person and their GP around health and wellbeing, and information on potential markers of recurrence/secondary cancers and information on what to do in these circumstances, and
  - a cancer care review in primary care.
- Use of patient activation measures (if this has been implemented locally).
- State what elements are commissioned/provided by the NHS and the Local Authority.

Note: it is very likely that some of the support for Health and Wellbeing for people affected by cancer will be the same as, or similar, to the

<b>Draft metric LWBC009 for Health and Wellbeing Information and Support</b>	
	services needed for people with other long term conditions - such as counselling, diet, weight management, exercise, employment/work, benefit support etc.
Source of numerator	CCGs or STPs
Definition of denominator	The number of CCGs/STPs in the Alliance
Source of denominator	Cancer Alliance
Methodology	<p>The number of CCGs/STPs with a comprehensive health and wellbeing support offer that meets the needs of people affected by cancer divided by the number of CCGs/STPs in the Cancer Alliance.</p> <p>For example: 3 out of 5 CCGs in an alliance have documented their comprehensive Health and Wellbeing Information and Support offer = 60% achievement of the metric.</p>
Data quality	To be determined
Unit	Percentage
Year type	Financial
Frequency and data lag	<p>Annually</p> <p>Data lag to be determined.</p>
Interpretation	If a CCG/STP does not have a 'Health and Wellbeing Information and Support for people affected by cancer' document/directory, this would be interpreted to mean that they are not yet fully working towards optimising the accessibility of health and wellbeing support for people affected by cancer in their population. It does not mean there is no health and wellbeing support being provided.
Further information	<p>In future, this metric could develop into a more comprehensive checklist of requirements whilst still acknowledging the need to develop Health and Wellbeing Information and Support in a way that best meets the needs of the population, STP priorities and the challenges that individual STPs face. [This work will begin in 2019]</p> <p>The metric could also be enhanced locally by including patient feedback (possibly through local surveys and/or the National Cancer Patient Experience Survey).</p> <p>The document should be publicly available and shared very widely to all professionals, services and partner organisations that support people affected by cancer. It is intended to serve as a resource to ensure that all people have access to information, support and services that meet their holistic needs from diagnosis onwards.</p>

<b>Draft metric LWBC009 for Health and Wellbeing Information and Support</b>	
References	<p><u>Resources available from Macmillan Cancer Support</u></p> <p>Recovery Package webpage <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package</a> (accessed 25 June 2019)</p> <p>including: Health and Wellbeing Support Events How To Guide <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774</a> (accessed 25 June 2019)</p>

<b>Draft metric LWBC010 for Cancer Care Reviews</b>	
Metric number	LWBC010
Metric short name	Cancer Care Reviews in primary care
Metric full name	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.
Rationale	<p>This metric has been an official Quality and Outcomes Framework (QoF) indicator for primary care for many years<sup>26</sup> although they are not mandatory.</p> <p>QoF is currently under review by NHS England (April 2019) and the current Cancer Care Review indicator definition (above) will continue during 2019/20. Until any changes are announced, this metric will use available published QoF data for 2017/18.</p> <p>Some CCGs have schemes that replace this QoF indicator, in which case a local decision should be made as to if and how the local alternative metric can be used in place of the national QoF CAN003 indicator.</p> <p>A CCR is a discussion between a patient and their GP or practice nurse about their cancer journey. It helps the person affected by cancer understand what information and support is available to them in their local area, open up about their cancer experience and enable supported self-management. It therefore complements the NHS England model of comprehensive personalised care.</p> <p>The <i>NHS England Long Term Plan</i><sup>27</sup> released in January 2019 states the ambition to deliver personalised care for all people and transform follow-up care, empower people to manage their care and the impact of their cancer and treatment and ensure follow-up care tailored to the individual.</p> <p>Personalised care for all people and transform follow-up care will ensure</p> <ul style="list-style-type: none"> <li>• Surveillance and aftercare that is tailored to individual needs – supported self-management, shared care or complex case management.</li> <li>• Personalised care to address holistic needs from diagnosis onwards, including needs assessment, care plan and health and wellbeing support.</li> <li>• Quality of life metric to demonstrate how well people are living beyond treatment.</li> </ul> <p>The Long Term Plan states the following ambitions;  <i>“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care</i></p>

<sup>26</sup> <https://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/quality-and-outcomes-framework>

<sup>27</sup> <https://www.england.nhs.uk/long-term-plan/>

<b>Draft metric LWBC010 for Cancer Care Reviews</b>	
	<p><i>plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing.”</i></p> <p>The interventions to support personalisation of care (formerly known as Recovery Package) will be delivered in line with the NHS Comprehensive Model for Personalised Care<sup>28</sup>. CCRs was one of the core components of the Recovery Package.</p> <p>Improving cancer follow up was one of the key ambitions in the report, <i>Achieving world-class cancer outcomes: a strategy for England 2015-2020</i>, published by the Independent Cancer Taskforce in July 2015. The Taskforce recommended that NHS England should accelerate the commissioning of services for patients living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the Recovery Package by 2020, [including] “<u>A cancer care review to discuss ongoing needs and completed by the patient’s GP or practice nurse</u>”.</p>
Definition	<p>As per QoF:</p> <p>Cancer CAN003: The percentage of patients with cancer, diagnosed within the preceding 15 months, who have a patient review recorded as occurring within 6 months of the date of diagnosis,</p> <p>NICE 2012 menu ID: NM62 6 points.</p> <p>Note:  Macmillan provide a ‘<a href="#">Ten Top Tips</a>’ guide for carrying out effective CCRs.</p>
Data source	<p><a href="https://qof.digital.nhs.uk/">https://qof.digital.nhs.uk/</a></p> <p>2017/18 data available here  <a href="https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2017-18">https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2017-18</a></p> <p>2016/17 data available here  <a href="https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/quality-and-outcomes-framework-qof-2016-17">https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/quality-and-outcomes-framework-qof-2016-17</a></p>

<sup>28</sup> <https://www.england.nhs.uk/personalisedcare/>

<b>Draft metric LWBC010 for Cancer Care Reviews</b>	
	Data is available at a GP practice, CCG, STP, sub-regional and regional and national level.
Indicator production	See above
Definition of numerator	See above
Source of numerator	See above
Definition of denominator	See above
Source of denominator	See above
Methodology	See above
Data quality	See above
Unit	Percentage
Year type	Financial
Frequency and data lag	Annual Approx. 7 months from end of financial year.
Interpretation	Interpret the data as per usual approach to QoF data interpretation.
Further information	<p>The QOF lacks clarity about what the CCR should consist of and what is helpful and necessary to include. As a result, the current experience of a CCR for the person affected by cancer can be variable.</p> <p>Macmillan are working with leading GP IT system providers, INPS Vision, SystemOne and EMIS, to develop electronic CCR templates similar to those for other chronic diseases to ensure consistency and quality.</p>
References	<p>NHS Digital QoF pages  <a href="https://qof.digital.nhs.uk/">https://qof.digital.nhs.uk/</a> (accessed 25 June 2019)</p> <p><u>Resources available from Macmillan Cancer Support</u></p> <p>Recovery Package webpage <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package</a> (accessed 25 June 2019)</p> <p>including: Ten Top Tips for carrying out an effective Cancer Care Review  <a href="https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774">https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774</a> (accessed 25 June 2019)</p>