

# London personalised cancer care: Key performance indicators

KPIs endorsed by the  
London Personalised Cancer Care  
Partnership Board (17 March 2020)

And revised following development of PSFU principles during COVID-19 (Sept 2020)

**Document review date:** Q4 2021/21 or when NHS England/Improvement publishes national data definitions (whichever is soonest)

## 1. Acknowledgements

A task & finish group was established, chaired by the Transforming Cancer Services Team and met three times before endorsement by the Partnership Board in March 2020. During August-September, they were revised in light of COVID-19 by TCST, Macmillan and the Alliances.

With thanks to the following people for their involvement in developing these KPIs:

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Sharon Cavanagh	Programme Lead	North Central & East London Cancer Alliance
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Mairead Griffin	Director of Nursing (Cancer); London Lead Cancer Nurses Forum	Guys & St Thomas' NHS Foundation Trust
Janice Minter	Lead Cancer Nurse; London Lead Cancer Nurses Forum	St Georges University Hospital NHS Trust
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## 2. About this document

Transforming Cancer Services Team, Macmillan Cancer Support, North Central & East London Cancer Alliance, RM Partners and South East London Cancer Alliance have developed regional key performance indicators (KPIs) for personalised cancer care interventions and personalised stratified follow-up pathways.

These KPIs are based on the NHS England Living with and Beyond Cancer (LWBC) data definitions, London commissioning intentions for LWBC developed in 2013 and the experience that we have gained in implementing those intentions over the last six years in the capital.

Furthermore, [NHS Long Term Plan](#) prioritises the personalised cancer care interventions for local delivery – Personalised Care and Support Plans (PCSPs) using Holistic Needs Assessment tools (HNAs), end of Treatment Summaries (TS), Health and Wellbeing Information & Support (HWBI&S) and personalised stratified follow-up (PSFU) pathways for breast, colorectal and prostate cancers.

### Five-year deliverables



#### **Personalised care**

- By 2021 everyone diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.
- By 2020 all breast cancer patients will move to a personalised follow-up pathway once their treatment ends, and all prostate and colorectal cancer patients by 2021.
- From 2021, the new Quality of Life Metric will be in use locally and nationally.

2019/20 deliverables for Cancer Alliances were as follows:



## Personalised Care deliverables 19/20

Personalised care	Breast Cancer	From April 2020 approximately two-thirds of patients who finish treatment for breast cancer to be on a supported self-management follow-up pathway
		From diagnosis, all breast cancer patients (including secondary cancer) to have access to personalised support
	Prostate Cancer	All Alliance Trusts to have in place protocols for stratifying the follow up of prostate patients and systems for remote monitoring for these patients
		From diagnosis, all prostate cancer patients (including secondary cancer) to have access to personalised support
	Colorectal Cancer	All Alliance Trusts to have in place protocols for stratifying the follow up of colorectal patients and systems for remote monitoring for these patients
		From diagnosis, all colorectal cancer patients (including secondary cancer) to have access to personalised support

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The [2020/21 NHS Operational Planning and Contracting Guidance](#) also specifies that Cancer Alliances should prioritise the following actions, which will support both operational performance as well as the delivery of the ambitions in the NHS Long Term Plan:

- Implementation of personalised stratified follow up pathways for colorectal and prostate cancer by April 2021 and ensure that at least two thirds of breast cancer patients benefit from stratified follow up.
- Use new patient level data to track delivery of the personalised care commitments for cancer patients in Cancer Outcomes and Services Dataset (COSD).

London's Lead Cancer Nurses Forum and Macmillan Personalised Cancer Care Project Managers Community of Practice were consulted specifically regarding the time point around diagnosis in which the HNA should be delivered – i.e. within 6 weeks of the individual receiving their diagnosis or the 31-day decision to treat to first definitive treatment standard (cancer waiting times denominator).

Thresholds have been agreed collaboratively and were endorsed by the pan London Personalised Cancer Care Partnership Board in March 2020. The definitions will be reviewed in Q4 2020/21 or when NHS England/Improvement publish data definitions, whichever happens soonest.

For more background and detail, this document should be read in conjunction with:

- NHS England cancer programme data definitions (draft at June 2019)
- [Macmillan Priorities for the NHS Long Term Plan](#) (2018)

### 3. London Principles

The following have been agreed as core KPI principles for London:

- We will continue to strive for ambitions set out by previous commissioning intentions, and collect a level of data that is more detailed than recommended by the NHS England/ Improvement 2020/21 planning guidance for cancer alliances. This is because we recognise all the hard work and collaboration that has taken place in London since the National Cancer Survivorship Initiative (2013), with the aim of improving care and support for people and their families.
- We support the NHS ambition to be a paperless NHS and so will reduce the number of HNAs and TS forms completed in hard copy.
- NHS England/ Improvement's expectation to report metrics via the COSD for HNA and TS is welcomed. This will support standardisation in reporting and raise visibility of these interventions taking place across England. It will also help to reduce the burden of reporting by patient facing teams. It is recognised however, that the majority of London services are not reporting to the latest version of COSD at present and changes are required to make this happen. Furthermore, there is a significant lag between data capture and national reporting (up to 18 months behind data capture).
- London continues with its ambition that copies of the HNA (including care plan) and TS will be shared with the patient and their GP practice within one week (electronically where possible) to support patients to self manage and for continuity of care.
- London recognises that HNAs can take place at any time along the pathway and care plans should be refreshed as part of this process. Please refer to the following draft national metrics (circulated in June 2019): LWBC004 – A, B, LWBC005, LWBC006 – A, B, LWBC007 – A, B.
- Since London started measuring the implementation of the interventions, it is evident that variation in data collection and reporting exists. Through feedback, discussion and evaluation, it is acknowledged that flexibility is required in data collection because of:
  - Pragmatic, reporting reasons
  - Ensuring we measure what matters to patients.

Therefore, the London KPIs are flexible in recognition of these two factors and are in the best interests of both patients and services.

- It is also recognised that consistent reporting via dashboards and exception reporting is welcomed across London. RM Partners kindly produces once-for-London dashboards on a quarterly basis. An exception report template (Appendix 1) has been designed for use by London's cancer alliances to share with regional and sub-regional boards.
- LDN KPI 1-3, 5 – Denominators will vary for a range of reasons. It is recognised that this may generate some double counting unless the intervention is directly linked to individual NHS numbers. The following approach is to be taken to allow for flexibility:
  - Date patient is informed of diagnosis (Faster diagnosis standard). Where this date is not recorded, then use;
  - Date of decision to treat. Where this is not recorded, then use;
  - Date of diagnosis
- LDN KPI 2 - End of treatment is to remain defined as 'the end of a planned phase of treatment'. Alliances will need to work with Trusts to develop their own Standard Operating Procedures (SOPs) to localise this definition by cancer site.

- LDN KPI 1, 2 - London will capture all of the national HNA metrics, but the primary KPI for reporting on dashboards will be the “percentage of HNAs with a care plan” conducted around diagnosis and end of treatment.
- LDN KPI 2-5 – End of Treatment HNAs, Treatment Summary and Health & Wellbeing Interventions (HWBI) completion rates by cancer type should correlate (or exceed) stratified follow up rates where PSFU is being implemented. Where these do not correlate, Alliances will work with their Trusts to develop improvement plans for the quality and safety of personalised follow up/long term condition management.
- LDN QIP 4 – London has agreed to a change in focus regarding the health & wellbeing information and support offer for patients and their loved ones. This will now be measured as a quality improvement project rather than key performance indicator. We have revised our London definition to ensure it is meaningful for patients and the wider system, whilst also meeting the minimum standard of the draft national metric. This will take the form of an annual census to ensure patients receive adequate information and support to self manage. It also includes reference to the recently published [NHS England/ Improvement self assessment checklist](#).
- KPI 5 – as some patients are referred from one trust to another for their treatment, it is recognised that this will impact a treating Trust’s achievement against this standard. After consideration, it has been agreed that London will wait until there is a nationally defined process for re-allocating numbers of patient from treating Trusts back to their referring Trusts.
- KPI 5 - An additional metric has been included to record the numbers of patients on stratified follow up pathways for cancer types other than breast, colorectal and prostate. There will be no denominator or threshold for this metric and therefore is not a KPI.
- Although the majority of KPIs are quantitative, providers are encouraged to collect qualitative data at a local level, to look at the impact of personalised care interventions on patient experience and impact. For example, UCLH NHS Foundation Trust has developed quality guidelines for delivering HNAs.

## 4. London Key Performance Indicators

London has developed five KPIs for London's cancer services to provide *holistic care* so that people affected by cancer are supported to self manage. These KPIs will be monitored alongside mandatory data collection as specified by NHS England/Improvement through the Cancer Outcome Services Dataset (COSD) and data returns required of the Cancer Alliances.

A summary of the KPIs are as follows:

- LDN KPI 1: Percentage of individuals receiving a Personalised Care & Support Plan at diagnosis
- LDN KPI 2: Percentage of individuals receiving a Personalised Care & Support Plan at the end of treatment
- LDN KPI 3: Percentage of individuals receiving a Treatment Summary
- LDN KPI 4: Census of Health and Wellbeing Information & Support offer
- LDN KPI 5: Percentage of individuals (with breast, colorectal or prostate cancer) stratified onto a patient initiated follow-up (PIFU) pathway

## LDN KPI 1: Percentage of individuals receiving a Personalised Care and Support Plan, using Holistic Needs Assessment tool, at diagnosis

**Holistic Needs Assessment (HNA):** Macmillan eHNA tool or the HNA template embedded within Trust cancer systems (eg Somerset, Infoflex etc). Copies of the completed Personalised Care & Support Plan (PCSP) is provided to the individual with cancer and also sent to the GP. All services should be using electronic HNA tools by April 2020.

**At diagnosis:** This is to be conducted at a time that best meets the personal and clinical needs of the individual. In the event that an individual receives treatment at a different trust to the one in which they were diagnosed, the treating Trust should either receive a copy of the HNA conducted at the diagnostic centre or be advised if one is needed.

**Numerator:** The number of completed HNAs and personalised care and support plans at the time of diagnosis, by cancer type. One count per patient.

**Denominator:** Number of 1st treatments reported by the trust for Cancer Waiting Times within the same calendar quarter as the HNA. Until the implementation of COSD v9, and the official release of the 28 day Faster Diagnosis Standard (FDS), this will be taken solely from the 31 day 1st treatment standard.

Following the COSD/FDS release, the denominator will be revised to allow for the richer data available. The denominator will be the first date recorded from the options below:

- 1) A 28 day FDS (date the patient is informed of their cancer diagnosis) OR
- 2) A date of decision to treat OR
- 3) A date of diagnosis

Denominator data will be obtained via the national cancer waiting times system. Please note that this is a proxy only as it is recognised that most patients will not receive an HNA at end of treatment within the same quarter as decision to treat or diagnosis.

**Source:** Trust data returns

**Threshold:** 70%

**Monitoring Frequency:** Quarterly

**This KPI relates the following national metrics:**

- LWBC004 – A, B
- LWBC005
- LWBC006 – A, B
- LWBC007 – A, B

## LDN KPI 2: Percentage of individuals receiving a Personalised Care & Support Plan, using Holistic Needs Assessment, at the end of treatment

**End of treatment:** This refers to the point on the pathway when either:

- the individual has finished receiving all cancer treatment and is being discharged back to the GP, OR
- the individual will not receive any further planned treatment at the acute trust for six months or longer months, OR
- the individual is being transferred to palliative/end of life care services
- the individual is being discharged onto a personalised stratified follow up pathway

**Numerator:** The number of completed HNAs and personalised care and support plans at end of a planned phase of treatment, by cancer type. One count per patient.

**Denominator:** Number of 1st treatments reported by the trust for Cancer Waiting Times within the same calendar quarter as the HNA. Until the implementation of COSD v9, and the official release of the 28 day Faster Diagnosis Standard (FDS), this will be taken solely from the 31 day 1st treatment standard.

Following the COSD/FDS release, the denominator will be revised to allow for the richer data available. The denominator will be the first date recorded from the options below:

- 1) A 28 day FDS (date the patient is informed of their cancer diagnosis) OR
- 2) A date of decision to treat OR
- 3) A date of diagnosis

Denominator data will be obtained via the national cancer waiting times system. Please note that this is a proxy only as it is recognised that most patients will not receive an HNA at end of treatment within the same quarter as decision to treat or diagnosis.

**Source:** Trust data returns

**Threshold:** 70%

**Monitoring Frequency:** Quarterly

**This KPI relates the following national metrics:**

- LWBC004 - A, C
- LWBC005
- LWBC006 – A, C
- LWBC007 – A, C

## LDN KPI 3: Percentage of individuals receiving a Treatment Summary

**Treatment Summary:** This document summarises the treatment received from diagnosis through to the end of primary treatment\* in order to support the primary care team to provide care in the community. Information included within the summary includes: the secondary care on-going management plan, medications, possible symptoms indicating toxicity/consequences of treatment/recurrence. It also outlines the patient's understanding of their prognosis and recommended actions for the primary care team regarding future management (e.g. osteoporosis or cardiac screening).

Completion is the responsibility of the medical team and copies are sent to the individual with cancer and their primary care team.

The London agreed Treatment Summary template is available on Somerset and Infoflex software systems.

**\*End of primary treatment:** This refers to end of first treatment or treatments given. This could include any one, or combination, of surgery, radiotherapy, chemotherapy or biological therapies.

Please note the following:

- a TS should be completed as part of the protocol for all individuals discharged onto a personalised stratified follow up pathway
- Individuals who are managed by the specialist palliative care team only (either discharged from or never under the oncology service) are excluded.
- It is considered good practice for the patient and their GP to receive a copy (electronically where possible) of the treatment summary within one week of end of primary treatment.

**Numerator:** The number of people treated for cancer with a completed Treatment Summary

**Denominator:** Number of 1st treatments reported by the trust for Cancer Waiting Times within the same calendar quarter as the HNA. Until the implementation of COSD v9, and the official release of the 28 day Faster Diagnosis Standard (FDS) both scheduled for April 2020, this will be taken solely from the 31 day 1st treatment standard.

Following the COSD/FDS release, the denominator will be revised to allow for the richer data available. The denominator will be the first date recorded from the options below:

- 1) A 28 day FDS (date the patient is informed of their cancer diagnosis) OR
- 2) A date of decision to treat OR
- 3) A date of diagnosis

Denominator data will be obtained via the national cancer waiting times system. Please note that this is a proxy only as it is recognised that most patients will not receive an HNA at end of treatment within the same quarter as decision to treat or diagnosis.

**Source:** Trust data returns

**Threshold:** 70%

**Monitoring Frequency:** Quarterly

**This KPI relates to the following national metric:**

- LWBC008

## LDN QIP 4: Census of Health and Wellbeing Information & Support offer

**Health and Wellbeing Interventions (HWBIs):** Interventions may be delivered in either a group setting or 1:1 appointment with the healthcare professional (for example within an end of treatment clinic, Macmillan Information Centre etc). It is recommended that group events are delivered jointly between acute teams and primary, community, third sector colleagues. They may be designed and delivered locally or provided by another organisation specialising in health and wellbeing support. They may be provided virtually or in person.

The information and support provided assists individuals to self manage, particularly following the end of a planned phase of treatment. It provides an opportunity for the individual living with or beyond cancer, and their loved ones, to receive education and support to enable them to lead as normal and as active a life as possible.

It also provides opportunity for people to ask questions and:

- To gain information on self-management, physical activity, suspicious signs or symptoms to trigger contact with the medical team, and contact details for relevant health professionals.
- To be signposted to local services as appropriate
- To capture unmet need, for example where patients need to be referred or signposted to a service that doesn't exist or doesn't meet their specific needs.

To be classified as a Health and Wellbeing Intervention, core content must reference information provided by the NHS England metric, **Health and Wellbeing Information & Support Offer** (LWBC009 'Definition of numerator') and include as a minimum:

- Expert advice on **health promotion** - to minimise risk of recurrence and support healthy living. i.e. being physically active, nutrition, healthy weight management, smoking cessation. To include information/support to effect behavioural change.
- **Support** to ensure that individuals have the confidence and skills to manage their condition themselves – i.e. referral onward to rehabilitation and psychological support services as appropriate and signposting to local support groups or buddying services.
- **Information about complementary therapies** - how these therapies may help to facilitate wellbeing.
- Advice on **adjusting to life after treatment** – addressing fears of cancer recurrence.
- Information on **signs and symptoms of recurrence** and **potential consequences of treatment**. All events should clearly convey and reinforce the methods to activate fast-track access back into the system if there are any concerns regarding new symptoms or recurrent disease.
- Information and access to **financial and benefits advice**.
- **Vocational rehabilitation** – access to services for patients, information patients and carers can share with their employers.
- **Management of symptoms**. For example fatigue or physical discomfort.

### Optional content

- Mindfulness
- Motivational tools

- **If it is a site specific event, specific issues relevant to the individual's type of cancer.** For example colostomy care, prosthetic care, early detection and management of lymphoedema, body image & sexual function.

In London, it is recognised that reporting of patients attending Health and Wellbeing Information fluctuates between quarters depending on how the intervention is delivered. For 2020/21, Trusts are asked to report in a new format by way of an annual census and demonstrating service improvements based on patient experience, by multi-disciplinary teams.

### Quality Improvement requirements:

Trusts will need to show demonstrable evidence of improvements made to patients' health and wellbeing offer by the MDT/Trust and provide an annual report to their Cancer Alliance. The evidence will focus on the following areas:

- inequalities in access – for example, but not limited to:
  - \* vulnerable groups – eg homeless people, migrants, those with learning disabilities and/or mental health difficulties, those living in poverty, sex workers, people who are isolated
  - \* nine protected characteristics – age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation
- patient experience
- process improvement

The first report will act as a baseline and will outline which offers are cancer specific and which are open to all people affected by cancer (with numbers of referrals and attendees per year). The report may also be produced in partnership with other organisations delivering HWB I&S, such as Macmillan information centres, Maggie's centres etc. The data shared with the NHS will need to be anonymised in order to comply with European Union General Data Protection Regulations.

As part of the census report, Trusts will demonstrate that they have:

- entered all of their HWB group events on the Cancer Wellbeing London website ([www.cancerwellbeinglondon.org](http://www.cancerwellbeinglondon.org)) and processes introduced to signpost patients to it as an information resource routinely.
- Shared details their own services and any services they refer to, with Cancer Care Map ([www.cancercaremap.org](http://www.cancercaremap.org)) for inclusion in the CCM database. They will also liaise with their local STP to facilitate consistency with the Directory of Services compiled in their area.
- Conducted motivational interviewing training and delivery (through the train the trainer programme)
- Conducted analysis to compare current and previous years delivery of health and wellbeing information & support.
- Considered and addressed health inequalities specific to their population
- Completed the [NHS England/Improvement HWB self assessment checklist](#)

This evidence and report will be submitted to the Trust's Cancer board and the Cancer Alliance.

**Source:** Trust cancer systems, [Cancer Wellbeing London](#) website, National [HWB checklist](#)

**Monitoring Frequency:** Annual

**This KPI relates to the following national metric:**

- LWBC009

## LDN KPI 5: Percentage of individuals (with breast, colorectal or prostate cancer) stratified onto patient initiated follow-up pathway

**Personalised stratified follow-up pathway:** A model of follow-up in which the clinical team and the person living with cancer make a decision about the best form of aftercare based on the individual's clinical and personalised needs. Individuals enter either a professional led or a patient initiated follow up (PIFU) pathway:

- **Professional Led Follow Up Pathway:** The follow-up pathway in which individuals with cancer continue to have face to face, video, phone, or email contact with their clinical team as part of continuing follow up. Follow up may be led by doctors, nurses or specialist allied health professionals. Follow up may be delivered by the specialist team or by the primary care team.
- **Patient Initiated Follow Up Pathway:** The follow-up pathway in which patients are empowered with the knowledge and skills to self-manage their condition. They are given information about the symptoms to look out for and who to contact if they notice any of these alert symptoms, future scheduled tests, and how to contact the specialist team if they have any concerns. They do not receive any further outpatient appointments unless further investigations or support is required. PIFU may also be known as Open Access Follow Up (OAFU), Patient Triggered Remote Follow Up (PTFU) or Supported Self Management Follow Up (SSMFU).

Features of a PSFU pathway include:

The National Cancer Survivorship Initiative (NCSI, 2013) advises that individuals are assessed early in the treatment pathway to determine which follow-up process would best meet their needs and identified the following key features:

- **Effective needs assessment at the point of diagnosis and end of treatment** that identifies and addresses any outstanding needs and ensures the patient has knowledge and confidence to self-manage.
- **Removal of routine follow-up appointments** from the pathway. The results will be reviewed by an appropriately qualified staff member and the patient is informed of the results (as per clinical judgement and local protocols).
- **Good communication** between specialist, community and primary care teams
- **A robust remote monitoring system** to manage on-going surveillance tests and ensure no one is lost to follow-up
- **A system that allows rapid re-entry** into the specialist cancer service as required. This reassures individuals that they are able to access appropriate, named support quickly should they need it, without having to go via their GP.

Local analysis will be used to understand patient flows between referring trusts and treating centres, and how this affects local delivery against the London threshold.

For further information on stratified follow-up and supported self-management, please follow the links below:

- **London Principles, Checklist and Resources for PSFU-** due for publication in September 2020

- **NHS England PSFU Handbook** - <https://www.england.nhs.uk/wp-content/uploads/2020/04/cancer-stratified-follow-up-handbook-v1-march-2020.pdf>

**Numerator:** The number of people with breast, colorectal and prostate cancer who have been initially stratified on to patient initiated follow up pathway.

**Denominator:** Number of 1st treatments (breast, colorectal and prostate cancers only) reported by the trust for Cancer Waiting Times within the quarter. Please note that this is a proxy only - it is recognised that most individuals will not be stratified onto a PIFU pathway within the same quarter as decision to treat.

**Additional metric:** The number of people who have been initially stratified to a PIFU pathway by cancer type (other than breast, prostate and colorectal).

**Source:** Trust cancer systems

**Threshold:** Breast 70%, Prostate 40%, Colorectal 40%

**Monitoring Frequency:** Quarterly

**This KPI relates to the following national metric:**

- LWBC001 – A
- LWBC002 – A
- LWBC003 – A

## 5. Reporting

Trusts submit their local data to their relevant Alliance contact within six weeks of the end of the CWT reporting period. The Alliances then submit their data to RM Partners Informatics service on a quarterly basis for analysis. The Health and Wellbeing Census will be submitted to the Cancer Alliance annually within 6 weeks of the end of Q4.

On behalf of London, RM Partners will produce quarterly (overall and cancer site) dashboards for London's Cancer Alliance boards during 2020/21. Exception reports (Appendix 1) will be produced by the Cancer Alliances and shared with the following for oversight:

- STP Cancer Boards
- London Personalised Cancer for Care Partnership Board
- London Cancer Transformation & Improvement Board (previously the Cancer Commissioning Board)
- Macmillan Cancer Support (London Partnerships Team)

Bespoke reports may be produced on request, although this is subject to capacity at RM Partners. Please contact: [rmpartners.informatics@nhs.net](mailto:rmpartners.informatics@nhs.net)

## 6. Glossary

Term	Definition
Care Plan	A care plan is a written document (paper or electronic) that outlines the planned care for a patient, along with what support is needed to meet their identified needs. This may be through signposting or referral to other services; information on how to self-manage their condition or the consequences of their condition; and information on how to contact their team if they have any concerns. It should be updated as their needs change.
COSD	The Cancer Outcome and Services Data set (COSD) has been the national standard for reporting cancer in the NHS in England since January 2013. COSD v9.0 and Pathology v4.0 is the new version of COSD and comes into effect from 1 April 2020.
Date of diagnosis*	<p>Date of primary/non-primary cancer diagnosis (clinically agreed) is either the date:</p> <ul style="list-style-type: none"> <li>• the primary/non primary cancer was confirmed or</li> <li>• the primary/non primary cancer diagnosis was agreed               <ul style="list-style-type: none"> <li>○ this will normally be the date of the authorised Pathology Laboratory Service Report which confirms the primary/non primary cancer or</li> <li>○ if this date is not available, date of primary/non primary cancer (clinically agreed) will be the date of the Multidisciplinary Team Meeting.</li> </ul> </li> </ul>
Decision to treat*	A decision to treat is made when it is decided that the patient requires a specific treatment – the date recorded is the one on which a consultation between the patient and the care professional took place where a decision was taken to treat a patient.
Faster Diagnosis Standard*	A performance standard that patients should wait no longer than 28 days from initial referral by a General Practitioner to diagnosis or ruling out of cancer.
Health & Wellbeing intervention	An intervention that creates opportunities for people affected by cancer to meet and get essential information and support from clinical specialists, local providers, and other subject experts. They support people living with and beyond cancer, their carers' and their families to take control and participate in their short and long-term recovery, giving them necessary information and promoting positive lifestyle change.
Holistic Needs Assessment	<p>A tool that facilitates a supported conversation that enables a person with cancer to identify any concerns about any area of their life (including physical, emotional, practical, financial and spiritual), not just their cancer diagnosis and treatment. A patient may use a concerns checklist to help them identify any concerns that they may have and to rate them according to importance. This supports identifying priority needs to address which can then be discussed and a plan recorded for how the identified concerns or needs will be addressed (see Care Plan).</p> <p>There are a number of tools available including the Macmillan Holistic Needs Assessment &amp; Concerns Checklist.</p>

Personalised care	<p>Personalised care represents a new relationship between people, professionals and the system. It happens when we make the most of the expertise, capacity and potential of people, families and communities. Personalised care is based on 'what matters' to people and their individual strengths and needs. It also takes into account the people that they care for and those that may care for them.</p> <p>Personalised care gives people the same choice and control over their mental and physical health that they have come to expect in every other aspect of their life. A one-size-fits-all health and care system simply cannot meet the increasing complexity of people's needs and expectations.</p>
Personalised cancer care interventions	<p>Personalised care in cancer includes a range of interventions that <i>all</i> cancer patients should have. These interventions are:</p> <ul style="list-style-type: none"> <li>• Shared decision making about treatment and follow up options</li> <li>• Personalised care and support planning (including holistic needs assessments) at the time of diagnosis, at the end of treatment, and at times in between where there are significant changes (physical, emotional/psychological and social) for the patient</li> <li>• Treatment summaries provided to the patient and their primary care team at the end of a phase of treatment</li> <li>• Health &amp; wellbeing information and support</li> <li>• Holistic cancer care reviews and long term management in primary care</li> <li>• Personalised stratified follow up</li> </ul>
Personalised Stratified follow up <sup>1</sup>	<p>PSFU is a model of follow-up in which the clinical team and the person living with cancer make a decision about the best form of aftercare based on the individual's clinical and personalised needs. Individuals enter either a professional led or a patient initiated follow up (PIFU) pathway.</p> <ul style="list-style-type: none"> <li>• <u>Professional Led Follow Up Pathway</u>: The follow-up pathway in which individuals with cancer continue to have face to face, video, phone, or email contact with their clinical team as part of continuing follow up. Follow up may be led by doctors, nurses or specialist allied health professionals. Follow up may be delivered by the specialist team or by the primary care team.</li> <li>• <u>Patient Initiated Follow Up Pathway</u>: The follow-up pathway in which patients are empowered with the knowledge and skills to self-manage their condition. They are given information about the symptoms to look out for and who to contact if they notice any of these alert symptoms, future scheduled tests, and how to contact the specialist team if they have any concerns. They do not receive any further outpatient appointments unless further investigations or support is required. PIFU may also be known as Open Access Follow Up (OAFU), Patient Triggered Remote Follow Up (PTFU) or Supported Self Management Follow Up (SSMFU).</li> </ul> <p>As PSFU it is a core component of personalised care, PSFU should be introduced to the patient early in their cancer pathway. This is so that they are fully informed and understand the variety of ways in which they may be followed up after their initial treatment ends.</p>

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Recovery Package	<p>The Recovery Package is an old term which refers to the four main personalised cancer care interventions that were outlined in the NHS England Five Year Forward View and the Cancer Taskforce Strategy. These outlined a commitment to ensuring that <i>'every person with cancer has access to the elements of the Recovery Package by 2020'</i>. These elements still form part of an overall support and self-management package for people affected by cancer and refer to:</p> <ol style="list-style-type: none"><li>1. Holistic Needs Assessment and Care Planning</li><li>2. Treatment Summary</li><li>3. Cancer Care Review</li><li>4. Health and Wellbeing intervention</li></ol>
Supported self management <sup>2</sup>	<p>Supported self-management proactively identifies the knowledge, skills and confidence ('activation') people have to manage their own health and care, using tools such as the Patient Activation Measure® (PAM®).</p> <p><sup>1</sup>The self-management pathway is dependent upon the presence of other key components of the pathway including:</p> <ul style="list-style-type: none"><li>• a remote monitoring system to manage on-going surveillance tests</li><li>• effective needs assessments that identify and address any outstanding needs and ensure the patient has the knowledge and confidence to self-manage</li><li>• good communication between specialist and primary care teams</li><li>• a system that allows rapid re-access to the specialist team if needed.</li></ul>
Treatment Summary	<p>A Treatment Summary is a document (or record) completed by secondary care professionals, usually the multi-disciplinary team (MDT) after a significant phase of a patient's cancer treatment. It describes the treatment, potential side effects, and signs and symptoms of recurrence. It is designed to be shared with the person living with cancer and their GP.</p>

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\*ref: [www.datadictionary.nhs.uk](http://www.datadictionary.nhs.uk) for the Cancer Outcomes and Services Datasets

<sup>1</sup> NHS Improvement (Cancer): [Innovation to Implementation: Stratified Pathways of Care for People Living With or Beyond Cancer](#)

<sup>2</sup> <https://www.england.nhs.uk/personalisedcare/supported-self-management/>

## 7. Key contacts:

Macmillan Cancer Support: **Emma Tingley** [etingley@macmillan.org.uk](mailto:etingley@macmillan.org.uk)

North Central London Cancer Alliance: **Sharon Cavanagh** [sharon.cavanagh@nhs.net](mailto:sharon.cavanagh@nhs.net)

North East London Cancer Alliance: **Karen Robb** [karen.robb3@nhs.net](mailto:karen.robb3@nhs.net)

RM Partners: **Vanessa Brown** [Vanessa.brown5@nhs.net](mailto:Vanessa.brown5@nhs.net)

South East London Cancer Alliance: **Sam Tordesillas** [samantha.tordesillas@gstt.nhs.uk](mailto:samantha.tordesillas@gstt.nhs.uk)

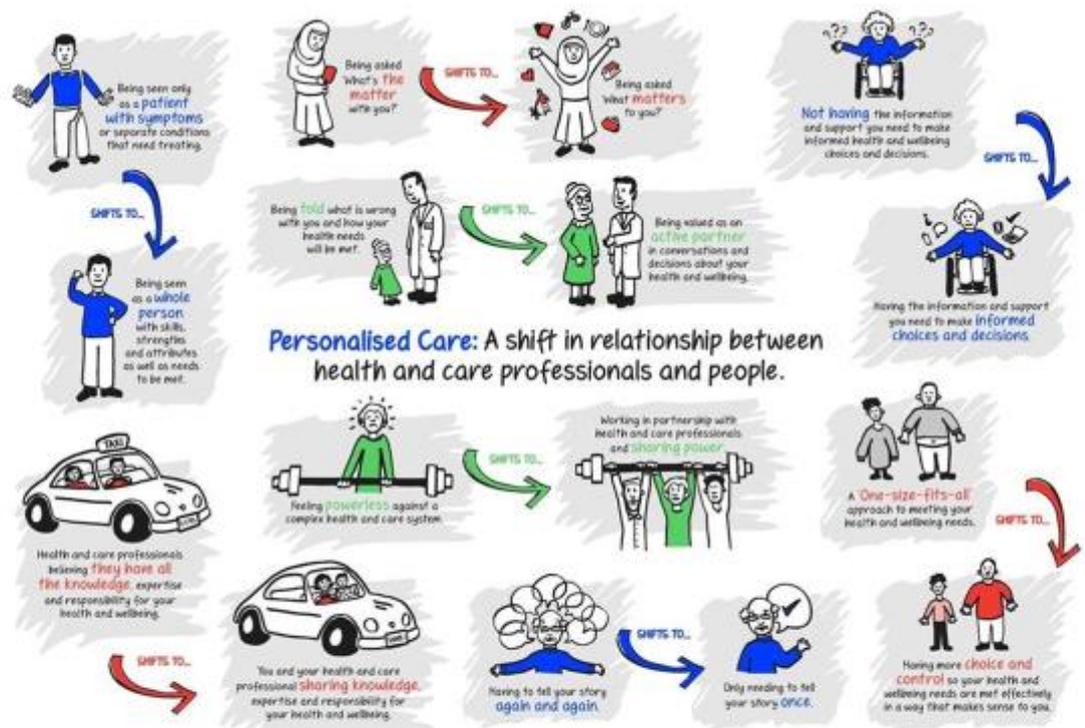
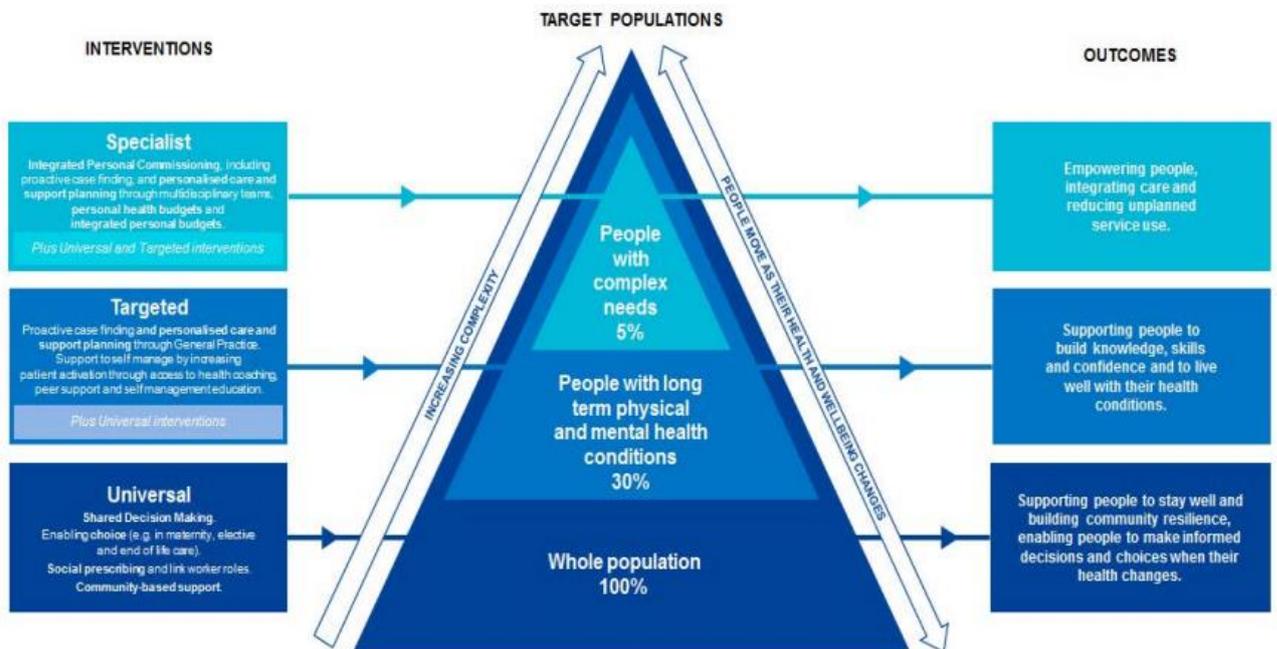
Transforming Cancer Services for London: **Liz Price** [England\\_TCSTLondon@nhs.net](mailto:England_TCSTLondon@nhs.net)

**Appendix 1 – London PC4C Partnership Board exception reporting template**

Personalised Cancer Care KPIs - Cancer Alliances in London																							
PC4C Alliance Leads			National deliverables																				
RM Partners	Vanessa Brown		<ul style="list-style-type: none"> <li>• Two-thirds of patients who finish treatment for breast cancer to be on a supported self-management follow-up pathway</li> <li>• All breast, colorectal and prostate cancer patients to have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support</li> <li>• All Alliance Trusts to have in place protocols for stratifying the follow up of prostate and colorectal patients and systems for remote monitoring for these patients</li> </ul>																				
SEL	Sam Tordesillas																						
NCL	Sharon Cavanagh																						
NEL	Karen Robb																						
Period	Quarter x 2020/21																						
KPI performance																							
Key Performance Indicators			RM Partners				South East London				North East London				North Central London				London				
LDN KPI #	Measure	London threshold	Current Quarter	Change since last quarter	Year to Date	Previous year end	Current Quarter	Change since last quarter	Year to Date	Previous year end	Current Quarter	Change since last quarter	Year to Date	Previous year end	Current Quarter	Change since last quarter	Year to Date	Previous year end	Current Quarter	Change since last quarter	Year to Date	Previous year end	
0	Improvement in receipt of quarterly data on interventions	N/A		🟡🟢🔴				🟡🟢🔴				🟡🟢🔴				🟡🟢🔴				🟡🟢🔴			
1	Implementation of HNA (with Care Plan at diagnosis)	70%																					
2	Implementation of HNA at end of treatment (with refreshed care plan)	70%																					
3	Implementation of Treatment Summaries at end of primary treatment	70%																					
4	Implementation of Health & Wellbeing Information & Support Offer	Annual census	Census report due Qxx			Census report due Qxx			Census report due Qxx			Census report due Qxx			N/A								
5a	Implementation of breast stratified follow-up (PIFU)	70%																					
5b	Implementation of colorectal stratified follow-up (PIFU)	40%																					
5c	Implementation of prostate stratified follow-up (PIFU)	40%																					
Exception report, with mitigating actions																							
KPI	RM Partners	South East London				North East London				North Central London													
0																							
1																							
2																							
3																							
4																							
5a																							
5b																							
5c																							

## Comprehensive Model for Personalised Care

All age, whole population approach to Personalised Care



This visual is a best practice example by the National Personalised Care team.

Image: Personalised Care Strategic Coproduction Group, 2019