Person-centred support for people affected by cancer: *delivering personalised care and support within Integrated Care Systems.*

Interim service specification

Macmillan LWABC programme: South Yorkshire, North Derbyshire, Bassetlaw and Wakefield. South Yorkshire, North Derbyshire and Bassetlaw Cancer Alliance.

February 2019

Version 1.3.2
**Executive Summary**

The Macmillan Living With and Beyond Cancer programme reached its halfway point in October 2018.

There is a lot to celebrate - and still some exciting progress to come.

The five year programme is specifically focusing on three areas – breast, colorectal and prostate – working with local NHS, local authority, voluntary and community organisations, as well as people affected by cancer at every stage, to introduce new integrated patient pathways for people living with and after a diagnosis of cancer.

The programme is delivering significant changes to the way cancer services are delivered and experienced by patients.

The changes require the development and implementation of three interdependent elements: Risk Stratification, the Recovery Package and supported self-management. In reality, this means making sure that every patient is offered a meaningful, person-centred conversation about their needs and linking people to support in their own communities.

The 2015/16 baseline for the three programme tumour sites estimates there are approximately 5,800 people diagnosed with a breast, colorectal or prostate cancer across the programme footprint each year. Macmillan Cancer Support estimates the number of people living with cancer in the programme area will increase from 74,000 in 2015 to 120,000 by 2030.

**Progress to date**

The programme, which started in April 2016, is seeing sustained engagement and progress across the eight CCG localities and six acute Trusts, through our seven locality steering groups.

And we already know we are having an impact.

Over 1,300 additional people affected by cancer have accessed support in just three out of the eight localities.

In some tumour sites, the number of diagnosed patients accessing support has risen from 31 per cent to 98 per cent and from 24 per cent to 75 per cent across some localities.

This has only been possible due to the sustained effort, energy and support of over 200 professionals and people affected by cancer across the eight localities.

We are also meeting national requirements for NHS England. In the latest NHSE LWABC temperature check, all localities are already offering or developing each element of the Recovery Package and Risk Stratification.

**How people affected by cancer have been involved so far**

The Macmillan Living With and Beyond Cancer programme includes commissioners, providers and
specialist providers from across the NHS, local authority, community and voluntary sectors, as well as high levels of patient, carer and public engagement.

People affected by cancer are heavily involved across the programme including the "co-design" of local services at place, recruitment of all new programme-funded posts and by sitting on a programme advisory board – parallel to the programme executive board – to help make decisions.

**NHS Long Term Plan**

The NHS Long Term Plan was published in January 2019. Whilst there are a number of changes in language relevant to the work of the programme, there is in reality now a greater alignment with our work to date. The new language reflects a shift from ‘Living with and beyond cancer’ and the ‘Recovery Package’ to ‘Personalised care and support’. This more accurately reflects our approach to the work we have been doing through the programme. There is agreement however at this stage of the programme there would be significant risks if we lost the known brand of the programme and stopped using the title of the ‘Macmillan Living With and Beyond Cancer programme’. Therefore this language will continue to be used to describe the programme, without any impact on the approach we have and will continue to take throughout the remainder of the programme.

**What’s next?**

Through the Macmillan Living With and Beyond Cancer programme, we are committed to making sure everybody receives the personalised care and support they need, when they need it, to help them to live well beyond a diagnosis of cancer.

As well as the continuation of locality and programme level projects with individual timelines, key upcoming milestones include Risk Stratification formally commissioned by CCGs in acute contracts from April 2019 onwards and alignment with programme evaluation team reporting timeframes in May 2019, January 2020 and September 2020.

Since the launch of the programme, we have seen a significant increase in the number of people accessing support in a way and place that works for them - and we’re proud to be making a difference.

As the programme matures, the focus up to the end of June 2021 will shift to concentrating more on supporting implementation, assessing impact and evaluation.

We look forward to sharing further results going forward.

*Richard Metcalfe, Macmillan Programme Lead, Macmillan Living With and Beyond Cancer programme.*

*February 2019*
Key learning from the programme to date

1. **It starts with a conversation** - The power of a local multi-disciplinary/agency steering group should not be underestimated. The programme’s success to date is built on collaborative, honest local ‘place-based’ conversations, people prepared to leave their organisation at the door, engagement, design and implementation, with the right people around the table, including robust local involvement of people affected by cancer at place. This approach moves the conversation from why? to how? It’s not all about the money: these conversation start change without investment.

2. **Change the narrative** – from “Recovery Package, HNA, TS, CCR” to “a person-centred conversation with a meaningful shared care plan” and ‘linking people to support in their own communities’, unlocking the significant role of the voluntary and community sector as well as community based services currently commissioned. Informed by a ‘theory of change’ approach to ‘unpacking’ the Recovery Package and Risk Stratification. Supported by high quality communications, working with patient engagement to develop case studies which help to tell the story.

3. **Shared realistic outcomes** – By working through the ‘theory of change’ approach have been able to be much clearer about what the programme will achieve in our expected outcomes and how. Localities are then in turn reviewing their own expected outcomes to align with the programme outcomes, to be more realistic, achievable and linked to the specific changes they are making.

4. **A common model in 'place-based' solutions** – It starts with a conversation (HNA), early in the pathway, but when?, with whom?, where? is now being tested across localities. New roles on the ground are now supporting people affected by cancer in both community settings and with acute teams supporting a better skills mix, already showing an impact: 19 additional posts to date with a further 6 in the pipeline for early 2019. All ‘place-based’ solutions are based on a common model:

![Diagram of common model](image)

* MISS – Macmillan Information and Support Service
5. **Timing** - ‘The stars align’ – all organisations have prioritised LWABC and we are seeing sustained engagement and progress across the eight CCG localities and six acute Trusts, through our seven locality steering groups. This has only been possible due to the sustained effort, energy and support of over 200 professionals and people affected by cancer across the eight localities.

6. **Supporting more people affected by cancer** - Involving CNS/clinical teams in the design of the solution, often moving towards the principle of ‘opt out’, leads to increased referral for support. Where a CNS is part of the conversation we are seeing significant increases in referral rates for support. The important role of community assets/resources, linking people to the support they need, balanced with community and acute interventions has resulted in an additional 1300 people accessing support in just 3 of the 8 localities, up to 98% of diagnosed patients in some tumours sites and 75% of diagnosed patients across some localities.

**Key enablers supporting implementation**

- **Theory of change development** – by working through a theory of change approach we:
  - aimed to provide greater clarity about what we think the programme will achieve and how, placing emphasis on causality and explicit assumptions
  - strengthened the programme design, monitoring and evaluation.
  - agreed to revise over time as the programmes evolve and evidence becomes available

  This approach also enabled us to change our use of language, ‘changing the narrative’, across the programme from the technical names for interventions eg: HNA, Treatment Summary or Cancer Care review to more meaningful language which works for everyone across the programme.

- The **Project Definition Document (PDD)** process was developed to ensure consistency of approach and focus thinking in localities around the implementation of LWABC. The process involves challenging local thinking; sign off is required by the locality steering group, evidence of involvement of people affected by cancer, scrutiny from the Programme Advisory Board of people affected by cancer and a formal panel process to approve and refine the final proposal. This has resulted in collaborative ‘place-based’ conversations rather than ‘them and us’.

- The **Programme Advisory Board** is a group of people affected by cancer who support the programme to: make investment decisions (PDDs), assure that benefits for people affected by cancer are realised, advise the Prioritisation Panel and Programme Executive Board about the impact on patients and carers of issues being considered by the programme, ensure that the needs of patients and carers are given priority and challenge the thinking of those making decisions where necessary.

- **Clinical Delivery Groups** in Breast Colorectal and Prostate Risk, involving MDT leads, CNS, oncologists, Primary Care, managers, commissioners and programme representatives, have developed and signed off guidance for Risk Stratification across the programme footprint.

- **Project management capacity** – Whilst initially not a priority in all localities, we have seen LWABC project management posts develop in all localities to support implementation at place. These posts are now seen as critical to integrating care and support across the local system,
both within cancer services and across the wider local health and care system.

- **Generic ‘support worker’ roles:** “Cancer Support Worker”, “Cancer Care Co-ordinator”, “Key Worker”, “Advocate”, “Health and Well-being Practitioner” are all new roles supporting the implementation of LWABC. These roles have been supporting people affected by cancer since April 2017, in both community settings and with acute teams supporting a better skills mix, already showing and impact.

- **Who, in what context and why?,** has been a key mantra of the programme to date …. for example whilst NHS England metrics suggest the timing of HNA within 31 days of decision to treat and CCR within 6 months of the date of diagnosis, we know that as arbitrary dates these may not be the right times for any one individual. By taking a person-centred approach, the implementation of LWABC localities involves working with patients and clinical teams to identify when interventions work best and through evaluation we will understand the optimum times. This equally applies to who has the conversation, in which setting etc…

### Progress in the implementation of place-based solutions

At the end of 2018 we are seeing:

- **Implementation** - Priorities and bids agreed to support implementation of LWABC in all eight localities; implementation is progressing and evaluation starting in all localities. Based on shared outcomes and the implementation of the Recovery Package; there is a common model in ‘place-based’ solutions. Further bids in two localities are in development: focusing on support worker roles to enable implementation; based on learning from other localities, focusing on skills mix to support access to CNS.

<table>
<thead>
<tr>
<th>LWABC model</th>
<th>Programme priorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>eHNA &amp; Treatment summary (live Oct 2018)</td>
<td>Project manager</td>
</tr>
<tr>
<td>Project manager Anxiety &amp; Confidence (The Well)</td>
<td>Education, Health &amp; Wellbeing,</td>
</tr>
<tr>
<td>Cancer support workers</td>
<td>eHNA &amp; Treatment summary (live Oct 2018)</td>
</tr>
<tr>
<td>Primary care development</td>
<td>Cancer support workers</td>
</tr>
<tr>
<td>H&amp;WB incl volunteer &amp; peer support (Barnsley)</td>
<td>LWABC GP lead role</td>
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<tr>
<td>‘Opt out’ hospital to community model; whole ‘system’</td>
<td>Community advocacy project - volunteers linking people to support in the community (Rotherham)</td>
</tr>
<tr>
<td>Bassetlaw (Aurora)</td>
<td>(Doncaster &amp; Bassetlaw)</td>
</tr>
<tr>
<td>Doncaster Project manager Points/’Opt out’ Cancer support worker roles eHNA (live May 2018)</td>
<td>eHNA (live April 2018)</td>
</tr>
<tr>
<td>Living well additionally funded roles &amp; community eHNA (live May 2018)</td>
<td>Treatment summaries (live March 2019)</td>
</tr>
<tr>
<td></td>
<td>Community advocacy project - volunteers linking people to support in the community</td>
</tr>
<tr>
<td></td>
<td>(Doncaster &amp; Bassetlaw)</td>
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</tbody>
</table>

- **eHNA/Treatment Summaries** - live in 7/8 localities, with the final locality aiming to start testing by January 2019, all are based on the Macmillan ‘Concerns Checklist’, all are electronic versions
able to be shared across acute and community with eHNAs and Care Plans now starting to flow into Primary Care. Different systems are being used; Macmillan eHNA, Infoflex and eHNA in is now being tested in the Rotherham Electronic Patient Record (Meditech) and will link to new EPR systems as they come on-line. Treatment Summaries are in place in two of six programme Trusts and are being developed in the remaining localities, mainly in Infoflex, with go-live dates in 2019.

- **Risk Stratification** – guidance has been agreed by Clinical Delivery Groups, updated to include consequences of treatment and late effects and signed off by the Cancer Alliance board, CCG Accountable Officers and included in Cancer Alliance Commissioning intentions for 2019/20 contracts for all three tumour sites. Local implementation is now progressing across the programme footprint.

- **Remote monitoring**, to support the implementation of Risk Stratification, local plan and funding now confirmed for four of five local Trusts. Three acute providers are developing models in Infoflex and ICE to test in Prostate and Colorectal. Rotherham’s own PSA tracker testing live from July 2019.

- **Learning and development** - 450 people expressed an interest in 6 training topics: as a result 13 training courses have been offered. All 13 courses are fully booked with 3 sessions delivered so far and all delegates attended.

- **Evaluation** - meetings with each locality and evaluation provider Brightpurpose will be completed by mid-December. Additional business intelligence and analytics support secured to support evaluation. Programme level evaluation baseline will be completed by January 2019, along with updated versions of the programme 'Monitoring and Evaluation' framework and draft locality evaluation plans.

- ‘**Living with Cancer**’ - report now being finalised to inform next steps; to progress with localities via LWABC programme, via the Cancer Alliance/HEE workforce planning and to support early ICS conversations around Palliative and End of Life Care. High level summary – focus required on (i) culture: collaborative behaviours and permission (ii) process and workforce: person-centred / 'Meaningful Conversations', new roles, simplifying essential communication (iii) integration with LWABC interventions: for all patients not just those in recovery.

- **Where next for Living With and Beyond Cancer?** – in the next phase of the programme we will be developing conversations with localities in light of the progress being made and emerging policy, in areas such as:
  - The introduction of NHS England LWABC metrics
  - LWABC interventions for non-programme tumour sites - most placed based solutions, eHNA/TS systems etc… are already being implemented across all tumours sites.
  - The role of allied health professionals in supporting people to live well with and beyond cancer.
  - The parity of esteem for mental health and physical cancer care - in light of the programme approach to person-centred care, needs assessment and support based on expressed needs.
**Building the evidence base**

The NHS England LWABC ‘Temperature Check’ (September 2018) certainly shows we are making progress, however it still does not articulate the impact for patients, professionals nor the system.

### Increased referrals and eHNA data

We know we are seeing more people affected by cancer accessing support. Involving CNS/clinical teams in the design of the solution, often moving towards the principle of ‘opt out’, leads to increased referral for support. Where CNS/clinical teams are part of the conversation we are seeing significant increases in referrals rates for support. By valuing the important role of community assets/resources, linking people to the support they need, balanced with community and acute interventions, an additional 1300 people are accessing support in just 3 out of 8 localities, up to 98% of diagnosed patients in some tumours sites and 75% of diagnosed patients across some localities.

We also know that Holistic Needs Assessments enable conversations about individuals’ needs/concerns, allow people to consider what is important to them and facilitate more personalised care and support. Through our evaluation work, as we begin to analyse eHNA data, we start to understand the importance of what works for “who, in what context and why?” and develop a robust understanding of the expressed needs of PABC across the programme. Effective collection, mapping and analysis of eHNA data will result in a powerful commissioning/service improvement tool for all organisations, based on the expressed needs of people affected by cancer.
<table>
<thead>
<tr>
<th>Rank</th>
<th>Bassetlaw</th>
<th>Doncaster (LW)</th>
<th>Doncaster (CNS)</th>
<th>North D. &amp; Hardwick</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Physical concern&lt;br&gt;Tired, exhausted or fatigued</td>
<td>Practical concern&lt;br&gt;Finance</td>
<td>Physical concern&lt;br&gt;Tired, exhausted or fatigued</td>
<td>Emotional concern&lt;br&gt;Thinking about the future</td>
</tr>
<tr>
<td>2</td>
<td>Family concern&lt;br&gt;Children &amp; Partner</td>
<td>Physical concern&lt;br&gt;Eating/Appetite/Diet/Nutrition</td>
<td>Physical concern&lt;br&gt;Hot flushes</td>
<td>Emotional concern&lt;br&gt;Anxiety/Worry</td>
</tr>
<tr>
<td>3</td>
<td>Emotional concern&lt;br&gt;Sadness or depression</td>
<td>Family concern&lt;br&gt;Children &amp; Partner</td>
<td>Physical concern&lt;br&gt;Moving around (walking)</td>
<td>Emotional concern&lt;br&gt;Uncertainty</td>
</tr>
<tr>
<td>4</td>
<td>Emotional concern&lt;br&gt;Thinking about the future</td>
<td>Practical concern&lt;br&gt;Travel</td>
<td>Physical concern&lt;br&gt;Sex, intimacy or fertility</td>
<td>Physical concern&lt;br&gt;Tired, exhausted or fatigued</td>
</tr>
<tr>
<td>5</td>
<td>Practical concern&lt;br&gt;Finance</td>
<td>Practical concern&lt;br&gt;Mobility</td>
<td>Emotional concern&lt;br&gt;Thinking about the future</td>
<td>Physical concern&lt;br&gt;Eating/Appetite/Diet/Nutrition</td>
</tr>
<tr>
<td>6</td>
<td>Emotional concern&lt;br&gt;Uncertainty</td>
<td>Physical concern&lt;br&gt;Tired, exhausted or fatigued</td>
<td>Physical concern&lt;br&gt;Passing urine</td>
<td>Physical concern&lt;br&gt;Tired, exhausted or fatigued</td>
</tr>
<tr>
<td>7</td>
<td>Physical concern&lt;br&gt;Sleep problems</td>
<td>Physical concern&lt;br&gt;Sleep problems</td>
<td>Emotional concern&lt;br&gt;Sadness or depression</td>
<td>Physical concern&lt;br&gt;Sleep problems</td>
</tr>
<tr>
<td>8</td>
<td>Emotional concern&lt;br&gt;Anxiety/Worry</td>
<td>Physical concern&lt;br&gt;Pain</td>
<td>Physical concern&lt;br&gt;Sleep problems</td>
<td>Physical concern&lt;br&gt;Sleep problems</td>
</tr>
<tr>
<td>9</td>
<td>Emotional concern&lt;br&gt;Loneliness or isolation</td>
<td>Physical concern&lt;br&gt;Changes in weight</td>
<td>Physical concern&lt;br&gt;Changes in weight</td>
<td>Physical concern&lt;br&gt;Pain</td>
</tr>
<tr>
<td>10</td>
<td>Emotional concern&lt;br&gt;Loss of interest in activities</td>
<td>Emotional concern&lt;br&gt;Anger or frustration</td>
<td></td>
<td>Physical concern&lt;br&gt;Pain</td>
</tr>
</tbody>
</table>

**Similarities**
- Incidence of the same physical concerns
- Only concerns common to all localities are physical:
  - Tired, exhausted or fatigued
  - Sleep problems
- Physical concerns ranked 6 to 10, especially sleep/pain/weight

**Differences**
- Doncaster: Living Well (LW) and CNS
- Significant variation in incidence & rank between localities
- Incidence of emotional concerns (from 1 to 6)
- Incidence of practical concerns (from 2 to 6)
- Incidence of family concerns (2/30)

Average number of concerns - 8.4  
Assessment declined - 5.6%  
Pathway stage - 39% to 85% (up to the end of treatment)  
Care plan actions - average 1 action per concern, with the vast majority being patient actions

**Cancer support worker roles and the South Tees 'intervention tool'.**

‘Support worker’ roles are not new to health and care, neither are they new to cancer care, however they are now being introduced specifically to support the implementation of LWABC. They have different titles in different settings; “Cancer Support Worker”, “Cancer Care Co-ordinator”, “Key Worker”, “Advocate”, “Health & Well-being Practitioner”, however their functions are very similar. To ensure consistency across these roles the programme is sharing job descriptions, competency.
frameworks, induction plans and escalation processes.

These new roles, funded through the programme, are specifically designed to support the implementation of LWABC. These roles have been supporting people affected by cancer within the programme footprint since April 2017, in both community settings and acute teams and are already showing and impact. Where hosted in an acute setting they are a community facing role, they support a better skills mix within the clinical team and become experts in support services and linking people affected by cancer to information and support, based on their expressed needs.

Particularly in our acute settings, through the use of an ’intervention tool' designed by the South Tees Hospitals NHSFT, we already know that these roles create more capacity, release CNS time to support complex people with more needs and enable more HNA/conversations. We know that just 17% of the CSW workload can be attributed to administration tasks, with 70% of the role being focused on conversations with patients about what matters to them.

Living with cancer

During 2018 we undertook a piece of work within the programme, related to access to CNS/key worker/support workers in enabling more patient-centred care. We focused on the role of the LWABC model in supporting all people affected by cancer, not just those in ‘Recovery', nor arbitrary dates for interventions such as Holistic Needs Assessments or Cancer Care Reviews, which makes us focus on the first six months of a cancer journey. Therefore we wanted to explicitly consider the needs of those people who ‘Live with’ cancer for weeks, month or years.

We talked to over a 120 people in 6 locality-based workshops, mainly ‘professionals’ in workshops, group-based sessions and one-to-one engagement with people affected by cancer. This work highlighted:

• ‘Honest' discussions are a precursor to everything else
• Learning and development, importance of ‘soft skills’, change in culture needed
• Pathways are complex and individual, but HCPs with the right skills take complexity out of it for patients
• Pathways can be lengthy – knowing how to get back into pathway is essential
• Information sharing is vital and joined-up working – systems and working practices

The report is now being finalised to inform next steps; to progress with localities via LWABC programme, via the Cancer Alliance/HEE workforce planning and to support early ICS conversations around Palliative and End of Life care. The conclusions and recommendations from the report will require a focus on:

(i) Culture change: collaborative behaviours and permission
(ii) Process and workforce: person-centred / 'Meaningful Conversations', new roles eg: support workers and simplifying essential communication
(iii) Integration with LWABC interventions: for all patients not just those in recovery.

Looking forward – programme and locality evaluation

By working through the ‘theory of change’ approach, understanding attribution and assumptions, we have refreshed the programme outcomes. It has helped us change the narrative around the Recovery Package, clarify outcomes and focus on the question: “what is the impact for people
affected by cancer"?

This work then informed our invitation to tender (ITT) for our evaluation partner, draft programme 'Monitoring and Evaluation' framework and locality evaluation plans. In conversations with localities we are focusing on what Changes localities expect to happen as a result of the Actions they are taking, for example, we know:

- **Holistic needs assessments** enable conversations about individuals' needs/concerns, what is important to them, more personalised care and support
- **Support services/Hubs** help to link people to the support they need in their communities
- **Cancer Support Workers** provide more capacity, release CNS time to support complex needs, more HNA/conversations

In the programme Monitoring and Evaluation framework and locality evaluation plans we are considering outcomes in the following areas:

1. Outcomes for individuals
2. Outcomes for health professionals
3. Outcomes for the system

The detailed expected outcomes in each of the three areas can be found in section 2.2 of the attached specification.

The evaluation is progressing with each locality and our evaluation partners: Brightpurpose and Cloud Chamber. Additional business and intelligence and analytics support, integrated with the Cancer Alliance, has been secured to support the evaluation. The programme level evaluation baseline will be completed by the end of January 2019, along with updated versions of the programme Monitoring and Evaluation framework and draft locality evaluation plans.

As the programme matures, the focus up to the end of June 2021 will shift to concentrating more on supporting implementation, assessing impact and evaluation.

*Further iterations of this specification will be published in line with the programme evaluation reporting timeframes: May 2019, January 2020 and September 2020 and finally in line with the programme closure in June 2021.*
1. Population Needs

Local/National context and evidence base

Local context

The Living With and Beyond Cancer (LWABC) programme is a five-year programme being delivered in partnership with Macmillan Cancer Support, to introduce new integrated patient pathways for people living with and after a diagnosis of cancer across a population of 2.2 million. This collaborative partnership between Macmillan Cancer Support and NHS 'Commissioners Working Together' started in 2015, with the programme being formally launched in April 2016, and programme closure due in June 2021. 

The LWABC programme includes commissioners, providers and specialist providers from across the NHS, local authority, community and voluntary sectors, as well as high levels of patient, carer and public engagement including the “co-design” of services to meet the quality and clinical standards of the LWABC model of care.

The programme is specifically focusing on three service areas – breast, colorectal and prostate, working with local NHS, local authority, voluntary and community organisations as well as patients and the public at every stage. The programme is delivering significant changes to the way cancer services are delivered and experienced by the patients. The changes require the development and implementation of the following interdependent services:

- **Recovery Package** – a series of interventions that when delivered together can greatly improve outcomes for people affected by cancer. Interventions include Holistic Needs Assessment, Treatment Summary, Cancer Care Review, education and support.
- **Risk Stratification** – discharge and follow-up will be appropriate to each individual depending on their need and, where appropriate, provided closer to home.
- **Self-management** – supporting an individual living with or beyond cancer to live as full a life
as possible. This includes the promotion of healthy lifestyles, support to return to work, financial and emotional support.

This programme is the third phase of work regionally which builds on work from previous phases and nationally in the implementation of interventions to support people LWABC.

The programme is specifically focusing on three tumour sites: breast, colorectal and prostate. However it is acknowledged that the interventions being introduced at place should be accessible to all. Therefore all people affected by cancer will be able to access the LWABC interventions being introduced at place.

The Recovery Package (RP) consists of four interventions developed and tested by the NCSI in conjunction with Macmillan, which aim to improve outcomes for people living with and beyond cancer and reducing demand on services. Ensuring everyone has access to a RP by 2020 is a key recommendation (recommendation 65) in the 2015 Independent Cancer Taskforce Report: Achieving World-Class Cancer Outcomes. Along with the roll out of stratified follow-up pathways for breast cancer by 2020, with other tumour pathways to follow, is another recommendation in the Cancer Taskforce Report (recommendation 67) which NHSE is committed to.

There is currently discussion among key stakeholders about the critical factors to the success of the Recovery Package. Although there is evidence behind each of the recovery package interventions as single interventions there are evidence gaps in relation to how the elements work as a whole.

 Whilst an awareness of local inequalities has been take into account in the development of local place plans for LWABC and is required as part of the programme investment process, the collection of evidence of the expressed needs of people affected by cancer in local places will be used to

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inform future service planning to ensure services meet the needs of people affected by cancer in each place.

The health and care context for the programme is:

- a projected two-fold increase in the number of patients surviving cancer nationally by 2030 (currently around 2 million in the UK and expected to increase to 3 million by 2020 and 4 million by 2030).
- significant improvements in the longevity of patients with cancer - half of people diagnosed with cancer may live for 10 years or more afterwards
- significant co-morbidities as well as social and emotional needs for those living with and beyond cancer, with up to 20% of these needs being unmet within current models of care
- national development of evidence-based models of care for people living with and beyond cancer, which it is recommended will become the standard approach for services from 2020
- the introduction of national guidelines for services to support people living with cancer
- development of Cancer Alliances and Integrated Care Systems (ICS) for the development of cancer services, involving a broad range of stakeholders including patients and carers
- the move towards collaborative commissioning for cancer services based on larger population groups

Local prevalence

At the end of 2015 around 74,500 people across the programme footprint were living up to 21 years after a cancer diagnosis. It is estimated that this could rise to 118,500 by 203016.

- 7,658 people in Barnsley were living up to 21 years after a cancer diagnosis. This could rise to an estimated 12,360 by 2030.
- 4,078 people in Bassetlaw were living up to 21 years after a cancer diagnosis. This could rise to an estimated 6,580 by 2030.
- 10,228 people in Doncaster were living up to 21 years after a cancer diagnosis. This could rise to an estimated 16,500 by 2030.
- 3,803 people in Hardwick were living up to 21 years after a cancer diagnosis. This could rise to an estimated 6,140 by 2030.
- 10,659 people in North Derbyshire were living up to 21 years after a cancer diagnosis. This could rise to an estimated 17,200 by 2030.
- 8,298 people in Rotherham were living up to 21 years after a cancer diagnosis. This could rise to an estimated 13,390 by 2030.
- 17,162 people in Sheffield were living up to 21 years after a cancer diagnosis. This could rise to an estimated 27,690 by 2030.
- 11,582 people in Wakefield were living up to 21 years after a cancer diagnosis. This could rise to an estimated 18,690 by 2030.

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For comparison, rates of people living up to 21 years after a cancer diagnosis:

<table>
<thead>
<tr>
<th>Persons</th>
<th>England</th>
<th>South Yorkshire, Bassetlaw &amp; North Derbyshire Cancer Alliance</th>
<th>West Yorkshire Cancer Alliance</th>
</tr>
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<td></td>
<td>3270</td>
<td>3304</td>
<td>3208</td>
</tr>
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<td>2895</td>
</tr>
<tr>
<td>Female</td>
<td>3550</td>
<td>3638</td>
<td>3511</td>
</tr>
</tbody>
</table>

The 2015/16 LWABC programme baseline for:
- the three programme tumour sites, estimates there are approximately 5800 people newly diagnosed with a Breast, Colorectal or Prostate cancer across the programme footprint each year.
- all tumour sites, estimates there are approximately 16000 people newly diagnosed with cancer across the programme footprint each year.

The analysis of the programme data shows growth of up to 3% in the number of individual patients in the focus three tumour sites (Breast, Colorectal and Prostate). This growth is in line with the national picture.

Survival rates for the three programme tumour sites are improving over time, but still remain below the national average. However, the improvement across the programme tumour sites for 5 year survival rates shows a higher than average increase in survival rates.

Survival data for the programme suggests that in the case of colorectal cancer, locally, there is some correlation between health deprivation and 1 year survival rates: two of the three most deprived (by rank) localities have the lowest 1 year survival rates and North Derbyshire (least deprived) has the highest.

Nationally, there are higher mortality rates resulting from cancer for patients who are in the most deprived groups in society and “while mortality rates vary widely across the country, they tend to be highest in areas with significant levels of deprivation” 17.

The age profiles for the three specified tumour sites show that there is a large increase in number of people between the age groups of 40-44 and 45-49 (around double). This is owing, largely, to breast cancer. The largest number of people appear in the 65-69 year age group.

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National Context

Every two minutes someone in England will be told they have cancer. Half of people born since 1960 will be diagnosed with cancer in their lifetime. But now more than half of people receiving a cancer diagnosis will live ten years or more. An ageing population combined with increased survival rates means that the number of people diagnosed and living with cancer will continue to grow rapidly, even with improvements in prevention.

There is a recognition that for many people cancer should be viewed as a long-term condition, with increasing numbers of people surviving and living with the consequences of cancer and its treatment.

Costs to the health care system are significant: 70% of people with cancer are also living with another long-term condition, 700,000 people are living with cancer and three or more long-term conditions. Physical illness and co-morbid mental health problems raise total health care costs by at least 45% for each person with a long-term condition and a co-morbid mental health problem. The Five Year Forward View (FYFV) also noted that long-term health conditions consume 70% of the health service budget.


Cancer and mental health are strategic priorities for NHS England. The Five Year Forward View for the NHS highlighted the importance of shifts in how care is delivered, "the NHS will take decisive steps to break down the barriers in how care is provided between family doctors and hospitals, between physical and mental health, between health and social care".

[preceding footnotes have been numbered in superscript point 11 font, which for consistency should be used to replace these and subsequent point 5 numerals]


19 Macmillan Cancer Support (2015) The burden of cancer and other long-term conditions

20 The Kings Fund (2012) Long term conditions and mental health: the cost of co-morbidity
https://www.kingsfund.org.uk/projects/mental-health-and-long-term-conditions-cost-co-morbidity

21 NHS England (2016) The Five Year Forward View for Mental Health


Following the launch of the National Cancer Survivorship Initiative (NCSI) in 2007, the 2010 NCSI vision and Living with and beyond cancer: taking action to improve outcomes (2013), there is now recognition that how well people live (their quality of life) is as important as how long they live. One of the biggest challenges is ensuring that improving holistic person-centred support for people affected by cancer is given the same attention as support for the physical health difficulties associated with cancer.

As part of the NHS "cancer dashboard", a new ‘quality of life metric’ is currently being developed. This will provide, for the first time, an indication of how well people are living after cancer treatment and not just how long they are alive. Five pilot sites in England have been selected. The pilot and evaluation period runs from September 2017 until early 2019. Once the quality of life metric becomes part of the national cancer dashboard, holistic person-centred support, including psychological and emotional well-being, will have to be prioritised and for the first time regarded as central to maintaining quality of life with parity to physical health outcomes.

The psychological and physical impact of cancer

A diagnosis of cancer can be devastating. Psychological distress can be a common and understandable response to a diagnosis of cancer and living with and beyond cancer. The majority of people use a variety of resources to cope, including their own inner emotional resources and external support systems, for example family, friends, peer support, online forums or third sector organisations.

But for some people where there may be additional social and psychological adversity, these resources may be insufficient to manage the personal impact of cancer and distress. Dysfunction and poor health self-management may follow, having a significant impact on the person’s quality of life and on the lives of their families and carers.

- In the year following diagnosis, around 10% of patients will experience symptoms of anxiety and depression severe enough to warrant intervention by specialist psychological / psychiatric services. Such difficulties can also be seen in 10-15% of patients with advanced disease.
- 58% of people diagnosed feel their emotional needs are not looked after as much as their physical needs.

[preceding footnotes have been positioned outside the framed text, which for consistency should be applied to these also]
• Cancer patients have a 55% higher risk of suicide than those without cancer\textsuperscript{32}
• 240,000 experience mental health difficulties including moderate to severe anxiety, depression and post-traumatic stress disorder
• Even 10 years after treatment 54% of cancer survivors still suffer from at least one significant psychological issue\textsuperscript{33}
• 67% of carers experience anxiety and 42% experience depression. Of these over three quarters do not receive any support\textsuperscript{31}

Improvements in diagnosis, medical treatments and survival means that the cancer landscape is changing, so the scope and specification of cancer psycho-social care will need to change accordingly.

Many of the physical health consequences of cancer may also significantly impact on mental health and psycho-social functioning\textsuperscript{23}
• 500,000 living with poor health or disability after treatment for cancer,
• 350,00 living with chronic fatigue,
• 350,00 living with sexual difficulties
• 200,000 living with moderate to severe pain after treatment
• 150,000 living with urinary problems such as incontinence
• 90,000 living with gastro-intestinal problems such as faecal incontinence
• Up to 63,000 living with lymphoedema

The broader impact on holistic needs of people affected by cancer

The broader impact on holistic needs of people affected by cancer is well known, however far less published research is available.

Locally we know that Holistic Needs Assessments identify a range of practical and family concerns as well as emotional and physical concerns. From local implementation we know Holistic Needs Assessments enable conversations about individuals’ needs/concerns, allow people to consider what is important to them and facilitate more personalised care and support. Through our evaluation work, as we begin to analyse eHNA data, we start to understand the importance of what works for "who, in what context and why?" and develop a robust understanding of the needs of people affected by cancer (PABC) across the programme. Which will result in a powerful commissioning/service improvement tool for all organisations, based on the expressed needs of people affected by cancer.

Work undertaken by the National Cancer Research Institute (NCRI) has identified that of the £650m spent on annually on cancer research, just £9m is spent on research related to LWABC. As part of a project which started in 2017 NCRI has worked with people affected by cancer, health care professionals and cancer charities to identify the UK Top 10 Living With and Beyond Cancer research priorities.\textsuperscript{34}

\textsuperscript{34} NCRI (2018) UK Top 10 Living With and Beyond Cancer research priorities – \url{https://www.ncri.org.uk/lwbc/}. 
2. Outcomes

2.1 NHS Outcomes Framework Domains and Indicators

| Domain 1 | Preventing people from dying prematurely | ✓ |
| Domain 2 | Enhancing quality of life for people with long-term conditions | ✓ |
| Domain 3 | Helping people to recover from episodes of ill-health or following injury | ✓ |
| Domain 4 | Ensuring people have a positive experience of care | ✓ |
| Domain 5 | Treating and caring for people in safe environment and protecting them from avoidable harm | ✓ |

2.2 Expected outcomes

Outcomes for individuals
- People expect their individual needs to be identified and addressed as part of their care, and ask for it if they don't receive it.
- Peoples’ side effects, consequences of cancer and consequences of treatment are identified and addressed early
- People identify and talk about issues that are important to them – and they are prioritised and addressed as they change over time.
- People feel their care is personalised to them and their needs
- People feel they are facilitated to understand their diagnosis and its consequences and adapt their lives to adjust to it as needed
- People are better informed, have reduced anxiety and are empowered to participate in their own care through activation of their own agency and coping mechanisms.

Outcomes for health professionals
- Improved skills and competencies around caring for people with cancer
- Increased understanding of the life situation and what's important to the individual and can offer better support.
- Increased awareness and confidence around providing care for people with cancer and identifying and discussing holistic needs, including confidence and knowledge of the model of assessing and meeting needs.
- Increased satisfaction through improved care delivery.

Outcomes for the system
- Better communication and co-ordination of care across secondary, primary and community care system
- Reduction in inappropriate or unnecessary appointments
- More proactive system response and planning based on improved understanding of need
- Reduction in unplanned service use across all settings eg emergency presentations, GP appointment, hospital admissions
- Better communication between acute and primary care means that GPs and practice nurses have better understanding of their patients’ treatment and ongoing needs.
3. Scope

3.1 Key aims and objectives of service

The programme is specifically focusing on three service areas – breast, colorectal and prostate, working with local NHS, local authority, voluntary and community organisations as well as patients and the public at every stage. The programme is delivering significant changes to the way cancer services are delivered and experienced by the patients. The changes require the development and implementation of the following interdependent services:

- **Recovery Package** – a series of interventions that when delivered together can greatly improve outcomes for people affected by cancer. Interventions include Holistic Needs Assessment, Treatment Summary, Cancer Care Review, education and support.
- **Risk Stratification** – discharge and follow-up will be appropriate to each individual depending on their need and, where appropriate, provided closer to home.
- **Self-management** – supporting an individual living with or beyond cancer to live as full a life as possible. This includes the promotion of healthy lifestyles, support to return to work, financial and emotional support.

The programme is specifically focusing on three tumour sites: breast, colorectal and prostate. However it is acknowledged that the interventions being introduced at place will be accessible by all people affected by cancer. Therefore **all people affected by cancer** will be able to access the LWABC interventions being introduced at place.

3.2 Service description / care pathway

3.2.1 NHS England LWABC Metrics and Recovery Package definitions

As a basic minimum, providers will ensure the delivery of the following, based on the current NHSE definitions for the national LWABC metrics due to be published in 2019.

The National Cancer Survivorship Initiative (2007-2011) highlighted the immediate and long term consequences of cancer and its treatment. As part of the NCSI, Macmillan Cancer Support in conjunction with the Department of Health (2013) developed the ‘Recovery Package’. Acute providers are expected to implement all interventions that relate to their services (HNA, TS, HWB) and in Primary Care (CCR), so that patients receive a package of care without variation. The Recovery Package has been considered as providing the “building blocks for achieving good outcomes” for those affected by cancer.
Improving cancer follow-up is one of the key ambitions in the report: Achieving world-class cancer outcomes: a strategy for England 2015-2020\textsuperscript{37}, 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, (reinforced in NHSE (2016) Implementing the cancer taskforce recommendations: commissioning person-centred care for people affected by cancer\textsuperscript{38}) with a view to ensuring that every person with cancer has access to the elements of the Recovery Package by 2020, including:

**Holistic Needs Assessment**
A holistic needs assessment and a written individualised care and support plan at key points along the pathway:
- A. Initial cancer diagnosis
- B. Start of treatment
- C. During treatment
- D. End of treatment
- E. Diagnosis of recurrence
- F. Transition to palliative care
- G. Other

**Treatment Summary**
- a treatment summary completed at the end of every phase of acute treatment, sent to the patient and their GP,
- information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years,
- potential markers of recurrence/secondary cancers and information on what to do in these circumstances and
- key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent.

**Cancer Care Review**
- a cancer care review to discuss ongoing needs and completed by the patient’s GP or practice nurse.
- occurring within 6 months of the date of diagnosis

**Health and Well-being support for people affected by cancer**
- access to a patient education and support event, such as a Health and Well-being clinic, to prepare the person for the transition to supported self-management, including advice on healthy lifestyle and physical activity
- signposting to rehabilitation, work and financial support services,
- information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years,
- potential markers of recurrence/secondary cancers and information on what to do in these circumstances, and

\textsuperscript{38} NHSE (2016) Implementing the cancer taskforce recommendations: commissioning person-centred care for people affected by cancer
• key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent.

However, currently there is discussion among key stakeholders about the factors critical to the success of the Recovery Package. Although there is evidence behind each of the Recovery Package interventions as single interventions, there are evidence gaps in relation to how the elements work as a whole.

3.2.2 Delivering the Recovery Package within Integrated Care Systems.

Therefore the approach tested to date through the LWABC programme suggests what needs to happen is - the offer of person-centred conversations, linking people to support in their community, as and when needed, recurring over time and in different locations, (acute, community, primary), as part of locally integrated services….. in a fully integrated way across service boundaries so that people affected by cancer experience seamless transitions in their care and support.

Figure 1 (below) describes the integration of the elements of the Recovery Package within person-centred integrated care systems.

* MISS – Macmillan Information and Support Service

The ‘how’ is as important as the model or framework. There are core elements and enablers (principles, competencies, assessments frameworks, systems, learning and development, risk stratification guidance, etc…) and core functions which may be done in different ways by different people according to locality and the local context. But fundamental to the model is working together across organisations at place, with the right people around the table, applying local service context, resources, skills and experience.
Essential functions:

- Dedicated project management time - critical to integrating care and support across the local system, both within cancer services and across the wider local health and care system.

- Stakeholders across the system build a ‘place-based’ integrated specification together with a view to an integrated model from the outset (rather than bolting on elements).

- Data sharing should be established / improved, focusing on the utilisation of integrated EPR systems across health and care at ‘place’.

- Locality steering with representation from across the system with a view to co-produce solutions between all stakeholders and agree competencies, data sharing systems, guidance, pathways. Also define responsibilities for learning and development, clinical engagement, patient engagement, good communications, across the settings

- A place-based population approach, with community engagement looking at services, assets, gaps, population, based on expressed need eg: HNA data.

- Designing or upskilling roles to be part of an integrated model with an emphasis on networking and understanding other professionals roles, avoiding duplication crossing boundaries, with clear role responsibility to support transitions of care

**Person-centred conversations with a meaningful shared care plan**

- **eHNA / eTreatment Summaries.** Providers will ensure an eHNA / eTreatment Summaries system is live by Q1 2019/20. They should be based on the Macmillan ‘Concerns Checklist’ / Treatment Summary template. Treatment Summary templates should be developed with clinical teams and may benefit from local adaptation. All versions should be shared across acute, primary care and community with eHNAs and care plans now starting to flow into primary care by Q1 2019/20. Whilst different systems are being tested: Macmillan eHNA, CiMs Infoflex and Meditech, they must be delivered in line with the specification in Appendix 1. eHNA is now being tested in the health and social care wide Rotherham Electronic Patient Record (Meditech) and it is expected that eHNA will link to new EPR systems as they come on-line.

- **‘Key/support worker’ roles** are not new to health and care, neither are they new to cancer care, however they are now being introduced specifically to support the implementation of LWABC. They are called a range of things “Cancer Support Worker”, “Cancer Care Coordinator”, “Key Worker”, “Advocate”, “Health & Well-being Practitioner”. To ensure consistency across these roles, the programme is sharing job descriptions, competency frameworks, induction plans and escalation processes.

  These new roles, funded through the programme, are specifically designed to support the implementation of LWABC. These roles have been supporting people by cancer within the programme footprint since April 2017, in both community settings and acute teams and are already showing an impact. Where hosted in an acute setting they are a community facing role, they support a better skills mix within the clinical team and become experts in support services and linking people affected by cancer to information and support based on their expressed needs.
Particularly in our acute settings, through the use of an 'intervention tool' designed by the South Tees Hospitals NHSFT, we already know that these roles create more capacity, release CNS time to support complex people with more needs and enable more HNA/conversations. We know that just 17% of the CSW workload can be attributed to administration tasks, with 70% of the CSW role being focused on conversations with patients about what matters to them. These roles should be ‘community facing’ experts in the clinical team, linking to support available across the community/outside the hospital. Providers should ensure that these roles should be provided in line with the Macmillan (2011) support worker competency framework.

- **Risk Stratification** – providers will ensure the delivery of risk stratified pathways for Breast Colorectal and Prostate cancers during 2019/20, in line with (i) the guidance agreed by the LWABC programme via the three programme Clinical Delivery Groups and published in October 2018 and (ii) the NHSI/NCIN ‘how to’ guide.

- **Remote monitoring** – providers will utilise remote monitoring to support the implementation of Risk Stratification. Providers will develop local plans and implement remote monitoring by Q1 2019/20. Acute providers are currently developing models in Infoflex and ICE to test in Prostate and Colorectal. Rotherham has developed its own PSA tracker to remotely monitor men diagnosed with prostate cancer. The guidance agreed by the LWABC programme via the three programme Clinical Delivery Groups (above) indicates which patients may be suitable for remote monitoring and from when this type of monitoring should be considered.

For suitable breast cancer patients, mammography scheduling in Trust radiology information systems is already used locally by providers.

Remote monitoring is a term used to describe how the specialist can schedule and monitor surveillance tests for patients who have completed treatment for cancer, without the need for a face-to-face outpatient appointment to convey the result. Its primary role is to support low-risk patients treated with curative intent that is suitable for a supported self-managed pathway. Remote monitoring systems should hold sufficient information to enable the clinician to manage the patient without the need to access case notes.

The traditional method of face-to-face follow-up is unnecessary for a large proportion of patients who attend outpatients simply to receive the result of surveillance tests.

Remote monitoring, as part of a support package for patients, offers an alternative model of care delivered closer to home. The risk of being ‘lost to follow-up’ in primary or secondary care is reduced. A robust IT solution ensures all patients suitable for a self-managed pathway who require surveillance tests, are monitored safely and appropriately for as long as necessary. It enables the release of outpatient capacity and reduces demand on clinical and secretarial resources.


**Linking people to support in their community**

It is clear that we can no longer expect individual professionals to retain the knowledge of the range of support services available to people affected by cancer at either a place or regional level. This support may be both cancer-specific services and generic support which is already available to all GP registered/local authority residents. This is particularly relevant for specialists nursing teams who are often unable to maintain the knowledge and referral criteria of existing services and new service developments outside the acute setting, beyond a limited ‘menu’ of frequently accessed services.

Therefore a hub/single point of contact enables people affected by cancer to be directed to one place. This approach simplifies the ‘pathway’ for people affected by cancer and professionals alike. This approach is very powerful when combined with an ‘opt out’ principle, where all people affected by cancer are offered a HNA and are able to decline support, based upon informed choice, as opposed to professional's gatekeeping services.

What we have seen through the programme to date is that involving CNS/clinical teams in the design of this solution alongside people affected by cancer and other stakeholders, often moving towards the principle of ‘opt out’, leads to increased referrals for support. We have seen an additional 1300 people accessing support in just 3 out of 8 localities, up to 98% of diagnosed patients in some tumours sites and 75% of diagnosed patients across some localities.

The role of the hub/single point of contact approach emphasises both (i) the critical role of community assets/resources, linking people to the support they need, balanced with community and acute interventions and (ii) interdependencies with community assets, other pathways for people affected by cancer with multiple conditions and existing commissioned services eg: IAPT and charitable sector.

The hub/single point of contact may be an existing support organisation such as NHS provider, community provider, Macmillan Information & Support Services or local cancer charity. The decision as to the number and location of the hub/single point of contact comes from a co-produced solution between all local stakeholders in each ‘place’.

If the hub/single point of contact is an existing service, it may play a key role in either eHNA, care planning and or care navigation, as well as delivering a range of support services ‘in house’.

Where there isn’t a physical hub or point of contact in the community, the role of the key/support worker is critical. As described above, these roles should be ‘community facing’, becoming experts in the clinical team, linking to support available across the community/outside the hospital.

Outside cancer services, similar interventions have proved to be effective across health and social care for a number of years. In addition Care Navigation in Primary Care and Social Prescribing are key strategies now being rolled out across the programme footprint. Whilst they differ in their approach and are suitable for people with different levels of need, they fundamentally support people to access local support in their local community and are key interfaces for the hub/single point of contact.
3.3 Commissioning services

New commissioning and contracting models are currently being tested across Integrated Care Systems, including localities within the programme footprint eg: Wakefield/Mid Yorkshire which has moved to an ‘Aligned Incentive Contract’. These new commissioning and contracting models are likely to feature in the NHS Long Term Plan due in January 2019.

Currently the ‘proactive’ commissioning of services varies. The most common forms of funding for services covered within this specification include:

- direct NHS commissioning: eg: acute and community services
- Macmillan grant funding
- charitable funding

Data from Holistic Needs Assessment is crucial to the future commissioning processes. Effective collection, mapping and analysis will result in a powerful commissioning/service improvement tool for all organisations, based on the expressed needs of people affected by cancer.

Further work needs to be undertaken to fully understand the impact on commissioning at place throughout the evaluation process. The programme evaluation approach, including the economic evaluation will be critical in informing the future approach.

3.4 Population covered, location and timing of services

It should be noted that providers and ‘places’ will be monitored by NHS England in line with the key performance indicators (s.5.2 below) for all people affected by cancer, from Q1 2019/20.

The programme is specifically focusing on three tumour sites: breast, colorectal and prostate. However it is acknowledged that the interventions being introduced at place will be accessible by all people affected by cancer. Therefore all people affected by cancer should be able to access the LWABC interventions being introduced at place.

3.5 Eligibility criteria, referral process and waiting times

As a basic minimum, providers will ensure the delivery of the interventions in NHSE definitions for the national LWABC metrics, due to be published in 2019. All people affected by cancer should be able to access interventions.

NHS England LWABC metrics suggest the timing of HNA within 31 days of decision to treat and Cancer Care Review within 6 months of the date of diagnosis.

“We, in what context and why?”, has been a key mantra of the programme to date …. we know that arbitrary dates may not be the right time for any one individual. By taking a person-centred approach, the implementation in LWABC localities is working with patients and clinical teams to identify when interventions work best and through evaluation we will understand the optimum time. This equally applies to who has the conversation, in which setting etc…

The approach tested to date through the LWABC programme suggests what needs to happen is -
the offer of person-centred conversations, linking people to support in their community, as and when needed, recurring over time and in different locations, (acute, community, primary), as part of locally integrated services..... in a fully integrated way across service boundaries so that people affected by cancer experience seamless transitions in their care and support.

Through the programme, stakeholders across the system are building a 'place-based' integrated solutions together with a view to an integrated model from the outset (rather than bolting on elements). The locality steering group with representation from across the system co-produce the solutions between all stakeholders and agree competencies, data sharing systems, guidance and pathways. By testing, evaluating and sharing learning across the programme we will understand “what works for whom, in what context and why?”

3.6 Partnership working with other services/providers

Implementing the Recovery Package within Integrated Care Systems starts with a conversation; the power of a local multi-disciplinary/agency steering group should not be underestimated. The programme’s success to date is built on a collaborative, honest local ‘place-based’ conversations, people prepared to leave their organisation at the door, engagement, design and implementation, with the right people around the table. Including robust local involvement of people affected by cancer at place. This approach moves the conversation from why? to how? and we have already seen that by involving the right people (eg: CNS/clinical teams) in the design of this approach solution, often moving towards the principle of 'opt out', leads to increased referrals for support.

Key partnerships and relationships include the following:
- Acute hospital providers
- NHS and Local Authority commissioners
- National and local cancer charities/support organisations
- Lead cancer nurse and CNS/clinical teams
- GPs and Primary Care staff
- Independent, voluntary and charitable sector organisations including hospices
- Key local service providers eg: IAPT services

4. Applicable Service Standards
The service will be delivered according to best practice and in line with the relevant local and national guidance.

4.1 Applicable national standards

- NICE guidelines – tumour site specific eg: CG175 Prostate cancer: diagnosis and management
- National Cancer Survivorship Initiative (2013) Living with and beyond cancer: Taking action to improve outcomes
- National Cancer Survivorship Initiative/NHS Improvement (2013) Innovation to implementation: Stratified pathways of care for people living with or beyond cancer. A ‘how to guide’

4.2 Applicable local standards

Providers will ensure there are local protocols/specifications/guidelines developed to support implementation at place. The expectation is that providers will use a range of standardised tools tested throughout the LWABC programme such as:

- Holistic Needs Assessment and Care Plan – the Macmillan Concerns Checklist and Care Plan.
- Risk stratification guidance - risk stratified pathways for breast, colorectal and prostate cancers, agreed by the LWABC programme via the programme Clinical Delivery Groups in 2018.
- Competency frameworks such as those developed for Support Workers (Macmillan 2011) and Clinical Nurse Specialists (Macmillan 2014)
- New roles such as Cancer Support Workers: job descriptions, induction plans, supervision arrangements, escalation planning, ongoing mentoring and support.

5. Applicable quality requirements and CQUIN goals

5.1 Outcome measures:

The collection of evidence of the expressed needs of people affected by cancer in local places will

be used to inform future service planning to ensure services meet the needs of people affected by cancer in each place.

“Who, in what context and why?”, has been a key mantra of the programme to date …. for example whilst NHS England metrics suggest the timing of HNA within 31 days of decision to treat and CCR within 6 months of the date of diagnosis, we know that as arbitrary dates these may not be the right times for any one individual. By taking a person-centred approach, the implementation in LWABC localities is working with patients and clinical teams to identify when intervention work best and through evaluation we will understand the optimum time. This equally applies to who has the conversation, in which setting etc…

In the programme Monitoring and Evaluation framework (Appendix 2) and locality evaluation plans we are considering outcomes in the following areas:

1. Outcomes for individuals
2. Outcomes for health professionals
3. Outcomes for the system

The detailed outcomes in each of the three areas can be found in ‘Expected Outcomes’ s.2.2 above.

5.2 Key performance indicators

5.2.1 NHS England LWABC metrics

As a basic minimum, providers will ensure the delivery of the following, based on the current NHSE definitions for the national LWABC metrics, due to be published in 2019. These are the proposed metrics for consultation with key stakeholders – August 2018.

<table>
<thead>
<tr>
<th>Metric number</th>
<th>Metric short name</th>
<th>Metric full name</th>
</tr>
</thead>
<tbody>
<tr>
<td>LWBC001A and LWBC001B</td>
<td>Personalised Follow Up for Breast Cancer</td>
<td>The proportion of people with breast cancer who have been stratified to (A) 'self managed' follow-up and (B) professional-led follow-up.</td>
</tr>
<tr>
<td>LWBC002A and LWBC002B</td>
<td>Personalised Follow Up for Colorectal Cancer</td>
<td>The proportion of people with colorectal cancer who have been stratified to (A) 'self-managed' follow-up and (B) professional-led follow-up.</td>
</tr>
<tr>
<td>LWBC003A and LWBC003B</td>
<td>Personalised Follow Up for Prostate Cancer</td>
<td>The proportion of people with prostate cancer who have been stratified to (A) 'self-managed' follow-up and (B) professional-led follow-up.</td>
</tr>
</tbody>
</table>
| LWBC004A, LWBC004B, LWBC004C, LWBC004D, LWBC004E, LWBC004F and LWBC004G | Holistic Needs Assessments for people affected by cancer | The number of completed Holistic Needs Assessments (HNA) at different points in the cancer pathway:
  A. Initial cancer diagnosis
  B. Start of treatment
  C. During treatment
  D. End of treatment
  E. Diagnosis of recurrence
  F. Transition to palliative care |
<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Metric</th>
</tr>
</thead>
<tbody>
<tr>
<td>LWBC005</td>
<td>Timely Holistic Needs Assessments for people affected by cancer</td>
<td>The proportion of people who have at least one completed HNA carried out within 31 days of first decision to treat for cancer.</td>
</tr>
</tbody>
</table>
| LWBC006A, LWBC006B, LWBC006C, LWBC006D, LWBC006E, LWBC006F, LWBC006G and LWBC006T | Personalised Care and Support Plans for people affected by cancer      | The number of completed Personalised Care and Support Plans at different points in the cancer pathway:  
A. Initial cancer diagnosis  
B. Start of treatment  
C. During treatment  
D. End of treatment  
E. Diagnosis of recurrence  
F. Transition to palliative care  
G. Other  
T. Total of A to G above |
| LWBC007A, LWBC007B, LWBC007C, LWBC007D, LWBC007E, LWBC007F, LWBC007G and LWBC007T | Holistic Needs Assessments leading to Personalised Care and Support Plans for people affected by cancer | The proportion 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. During treatment  
D. End of treatment  
E. Diagnosis of recurrence  
F. Transition to palliative care  
G. Other  
T. Total of A to G above |
| LWBC008  | Treatment Summaries for people affected by cancer                          | The proportion of people treated for cancer with a completed Treatment Summary |
| LWBC009  | Health and Wellbeing Support for people affected by cancer                 | The proportion of CCGs or STPs with a comprehensive health and wellbeing support offer that meets the needs of people affected by cancer. |
| LWBC010  | Cancer Care Reviews in Primary Care                                        | The percentage of patients with cancer, diagnosed within the preceding 15 months, who have a patient review [in Primary Care] recorded as occurring within 6 months of the date of diagnosis. |

### 5.3.2 LWABC Programme evaluation metrics

The programme level evaluation baseline will be completed by the end of January 2019, along with updated versions of the programme Monitoring and Evaluation framework and draft locality evaluation plans.

Both the programme and locality evaluation plans will define which metrics providers and ‘places’ will need to collect, in addition to:
The NHS England LWABC metrics in s.5.3.1 (above)

(ii) eHNA/treatment summaries – the data flow (import and export) as defined in the specification in Appendix 1.

5.3 Data collection

5.3.1 NHS England LWABC metrics

The NHS Long Term Plan due in January 2019, offers us a huge opportunity in cancer care work to build on the ambitions from the Taskforce, including in LWABC, and NHSE wants to ensure the work on LWABC data and outcomes aligns with this. Also, due to the nature of the work involved in launching new NHS metrics, there is a clear need to balance the need for data without overburdening services with data collection, when the appropriate IT is not available universally. Therefore further work is underway to agree a solution that provides this balance.

Key planned milestones: (still dependent on NHS Long Term Plan requirements)
- Immediate – Alliances and Trusts to focus on improving Trusts’ submission of HNA data to PHE as part of the COSD Cancer Outcomes and Services Dataset. HNA date and timepoint in pathway are now (from April 2018) required to include data items in COSD submissions.
- February/March 2019 – formal approval of standardised LWABC metric definitions. Local decisions can then be made regarding collection and use of LWABC metric data. Further information to follow early in 2019.
- February 2019 – consultation by PHE on new LWABC data items in COSD (Cancer Outcomes and Services Dataset).
- March 2019 - interim solution (to be agreed) on national use of metric data to monitor LWABC implementation in 2019/20 and 2020/21
- 2021 onwards – new LWABC data items collected in COSD (subject to the above consultation), allowing monitoring of more Recovery Package interventions and self-managed follow up.

5.3.2 LWABC Programme evaluation

The evaluation is progressing with each locality and our evaluation partners: Brightpurpose and Cloud Chamber. Additional business intelligence and analytics support, integrated with the Cancer Alliance, has been secured to support the evaluation.

The programme level evaluation baseline will be completed by the end of January 2019, along with updated versions of the programme Monitoring and Evaluation framework and draft locality evaluation plans.

The high level programme evaluation reporting timeframes are: May 2019, January 2020 and September 2020.
## Updated eHNA/eTreatment Summary specification, November 2018

<table>
<thead>
<tr>
<th>Item</th>
<th>Purpose</th>
<th>Output required</th>
<th>Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Electronic Holistic Needs Assessment tool (eHNA)</strong></td>
<td>Tool/mechanism to electronically input and record patient Holistic Needs Assessment and which automatically supports generation of an individualised Care Plan.</td>
<td>Tool integrated into trust Cancer Information System. (Compatible with Web end access)</td>
<td>Allows identification of the individual needs of people affected by cancer defined by them, to inform effective support, signposting and care planning. Improves efficiency and ‘value’ to patient of face-to-face appointments by ensuring they are structured around reviewing and addressing the needs arising from HNA. Encourages a person centred conversation. Core deliverable of the Recovery Package as defined by the national strategy for cancer, the regional LWABC programme and the SYB ICS priorities. Reduces paper processes and improve efficiency and consistency in delivery at Trust level. More time-efficient process for cancer site-specific nursing teams. Allows greater flexibility of delivery process. Adoption of learning and good practice from national testing. Inter-dependencies – utilisation of current Trust Cancer Information System Infoflex, would allow eHNA to be captured in same place as wider cancer record – supporting relevant data fields of the COSD (Cancer Outcomes and Services Dataset) and more auto-population ability of Treatment Summaries.</td>
</tr>
<tr>
<td><strong>eHNA care plan</strong></td>
<td>Tool/mechanism to electronically devise individual Care Plans based on the priorities identified by the patient through eHNA completion. This should be automatically triggered by the completion of an eHNA</td>
<td>Tool integrated into trust Cancer Information System. (Compatible with Web end design) Triggered by completion of eHNA with alert to site specific team Able to summarise in Treatment Summary</td>
<td>Structured, consistent format. Automatic trigger from eHNA completion allows teams to schedule dedicated time within job plans to formulate Care Plans. Formal document of output of eHNA with sharing and transferability beyond secondary care. This ensures that support resources can review, contribute to and update the Care Plan. Patient does not have to repeat history as outcome document shared.</td>
</tr>
</tbody>
</table>
Integral to the HNA is the Care Plan, which describes the agreed plan made as a result of the conversation held to address the identified concerns. This plan could include support, information, signposting and referrals to other services if required and will support people to self-manage where possible. This should minimise the risk of a crisis which can lead to emergency or unplanned care.

| **Treatment Summary** | To provide a comprehensive cancer treatment summary to improve the exchange of information between providers of care (and to the patient). | Functional Treatment Summary template within trust Cancer Information System that maximises automatic population ability from the wider cancer record. Template will include all core recommended components as defined by national TS testing. Template will include site-specific function and content to allow consistency in information and minimise the time required to complete Function allows archiving of previous versions Able to be added as an attachment to email and ICE (akin to Trust D1 process) | Informs the Cancer Care Review in primary care and remote monitoring/risk stratified models of care through more consistent exchange of robust cancer related information. The TS template includes:
- details of diagnosis - including READ codes for both diagnosis and treatment so that the GP can update their patient database and cancer register.
- indication on whether the patient should be added to the primary care palliative or supportive care register
- possible short-term treatment toxicities and side effects, including when urgent review is indicated
- information about the consequences /side effects of treatment
- alert symptoms that require referral back to specialist team: i.e. signs and symptoms of recurrence
- any required GP actions to monitor/support the individual
- summary of information given to the patient about their cancer and future progress
- summary of HNA and Care Plan

Sharing treatment information with patients makes sure that they are involved in their cancer journey and have the same information as health care providers.

Patients can use a Treatment Summary to
<table>
<thead>
<tr>
<th>IT consultancy support/ training for users</th>
<th>Technical support</th>
<th>Data flow (import and export)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IT support of local implementation and configuration. To enable users to be proficient in the use of all new relevant system components to maximise benefit and efficiency.</td>
<td>Supports governance and infrastructure and enables a more sustained system. Supports staff using the system. Builds regional capability to enable shared learning and support of other providers during wider rollout or system and processes.</td>
<td>To allow a data flow of information related to eHNA between the Trust's Cancer Information system and the national Macmillan eHNA system. Compatibility with the Macmillan system which does not compromise Information Governance requirements. This level of access is key and must be bi-directional, particularly in instances where patients have complex pathways or where their care is shared between a numbers of services. From an Infoflex point of view, it should be possible to configure the respective trust Cancer Information</td>
</tr>
<tr>
<td>Greater flexibility to deliver processes and consistent with national cancer strategy proposals to allow patients access to their records.</td>
<td>Safe, functioning web ended solution that is user friendly, supports key deliverables and does not compromise the security of the Trust’s IT system/s.</td>
<td>Supports national work of Macmillan and utilisation of data to inform strategy. Production of robust Trust level reports related to eHNA which: - enables services to understand patterns of delivery - enables learning and service modifications through improved understanding of emergent patient needs - Provides leverage and evidence to support the development of business cases (if gaps revealed) - Provides evidence which supports COSD and the National Quality Surveillance Programme - Trust would be able to utilise data to report performance against Key Performance Indicators (e.g. % of patients completing eHNA) Sharing of outcomes reduces burden on patient of repeating information.</td>
</tr>
</tbody>
</table>
System installations to talk to one another and interchange care plan information where appropriate. Transfer of data, and in particular coming from trust Cancer Information System to Macmillan system Require the ability for Macmillan to take identifiable care plans from trust Cancer Information system and attaching them to Macmillan and this is seen as being of critical importance. Non-secondary-care perspective interoperability. Any care plan written needs to be shared with the wider teams (NHS and Social) providing care and support for them.

<table>
<thead>
<tr>
<th><strong>Macmillan logo</strong></th>
<th><strong>Brand</strong></th>
<th><strong>Macmillan logo on each page of the eHNA</strong></th>
<th><strong>Raises awareness of Macmillan support and brand.</strong></th>
</tr>
</thead>
</table>

| **Tablets - compatible with Trust systems and would support Web access and functionality** | **To ensure there is the IT Infrastructure to enable electronic delivery of key parts of the Recovery Package Complies better with Trust Information Governance processes and reduces risk associated with paper processes** | **Purchase of portable IT devices which reflect the preferred specifications of the Trust Local configuration of devices** | **Greater flexibility for the clinical team and more ‘live’ data capture therefore promoting more efficient use of time Supports processes to deliver the Recovery Package** |

| **Remote monitoring module** | **To support the remote monitoring of cancer follow-up patients in line with risk stratified models that reduce face to face hospital visits whilst sustaining high levels of clinical governance and failsafe** | **Functional tool integrated in to trust Cancer Information System Interface with ICE reporting system to allow automatic feed of results and alert triggers for cancer surveillance if it** | **Supports risk stratified models of follow up which better facilitate support self-management. Reduces unnecessary and unproductive routine hospital follow-up appointments for the patient with associated cost and anxiety. Supports the Trust’s objectives around reducing new to follow up ratios. Integrated part of the Trust’s wider cancer** |
|   |   | allowed results to be pulled through into Infoflex
|   |   | Ability to map site specific follow-up protocols for individual patients
|   |   | Ability to generate ‘work lists’ to safely identify patients due surveillance components
|   |   | Built in letter templates re ‘standard’ surveillance outcomes
|   |   | Supports Trust activity reporting requirements consistent with national contracting standards
|   |   | Summary of ‘remote monitoring’ surveillance event which can either be electronically attached to patient record or printed off for written case notes.
|   |   | information system.
|   |   | Provides efficient electronic process for the remote monitoring of patients which is not paper-reliant or based on Excel spreadsheets.
|   |   | Supports more nurse-led follow-up initiatives.
|   |   | Allows better fail-safe measures to ensure follow up patients do not miss key surveillance tests or intervals.
Content of the Framework:
1. Purpose, scope, audiences
2. Outcomes x methods matrix (1,2,3)
3. Key Questions x methods matrix (1,2,3)
4. Core data x methods matrix (1)
5. Site specific tabs x methods matrices (2,3)
6. Gantt chart – timetable
7. Tools (survey questionnaires, audit tools, SSI guides, focus group discussion guides)
### 2. Outcomes x methods matrix

<table>
<thead>
<tr>
<th>Outcome (questions)</th>
<th>How will we know (measure/metric)</th>
<th>Tool/who/when etc</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theory 1: The Generic RP (and SP) model</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>1. Outcomes for Individuals</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1 People expect their needs to be identified and addressed as part of their care, and ask for it if they don’t receive it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Q: Is there an effective opt-out process?</em></td>
<td>% of patients offered HNA and care planning (is it routinely offered?)</td>
<td>Core data (audits/eHNA)</td>
</tr>
<tr>
<td><em>Q: What are the expectations of HPs and patients?</em></td>
<td>Health professionals see HNA &amp; CP as integral to care within the team</td>
<td>SSIs with HPs (2 rounds)</td>
</tr>
<tr>
<td></td>
<td>Patients experience of the offer (how was it explained to them?)</td>
<td>SSIs with patients who have been offered and received HNA &amp; CP (6 month cohort in each site)</td>
</tr>
<tr>
<td>1.2 Peoples’ side effects, consequences of cancer and consequences of treatment are identified and addressed early (TS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Qs Were TSs received by GPs?</em></td>
<td>% of TSs sent by Trusts/received by GPs</td>
<td>Core data (audits/eHNA)</td>
</tr>
<tr>
<td><em>Q Did they address side effects etc?</em></td>
<td>% using a standard template, addressing side effects etc</td>
<td>Audit of TS content (sent anonymised by Trusts)</td>
</tr>
<tr>
<td><em>Q Did people understand the content?</em></td>
<td>% of people who reported their side effects etc were explained to them</td>
<td>CPES # 15,16 (breast and colorectal) – plus bespoke prostate patient experience survey</td>
</tr>
<tr>
<td></td>
<td>Patient experience of TS and end of treatment conversation</td>
<td>SSIs (6 month cohort)</td>
</tr>
</tbody>
</table>
1.3. People identify and talk about issues that are important to them – and they are prioritised and addressed as they change over time

| Q | Did they feel able to talk about…. (why/why not?) | - Patient experience | - Patient survey and SSIs |
| Q | were their issues addressed (why/why not?) | - Patient experience | - Patient survey, SSIs (eg at 2nd HNA review of 1st) - Audit of HNAs and care plans |
| Q | How do concerns change over time (patterns) and in different settings and how can the system respond? | - # and range of concerns in different settings/times - Comparison of 1st HNAs with end of treatment HNAs (concerns still there/different?) - Patient experience | - Audit of HNAs and care plans - Audit/eHNA data linking 1st and subsequent HNAs & CPs (build into reporting template) - SSIs |
| Q | How would they have addressed these needs in absence of HNA & CP, where else might you have gone? (difference made) | - Patient perspective (quant – would have gone to eg GP, A&E, CNS, family, don’t know etc) (qual) | - Patient survey, SSIs (eg at 2nd HNA review of 1st) |

1.4 People feel their care is personalised to them and their needs (whole RP) (eg communication, information passed, needs identified and met)

| Q | To what extent did they feel care was personalised… (why/why not?) | - Patient perspective | - Patient survey x 2 - SSI x 2 |

1.5 People are better informed, have reduced anxiety, reduced severity of concern and are enabled to recognise and adapt their lives to ‘new normal’.

<p>| Q | To what extent did HNA &amp; CP reduce anxiety, severity of concerns (see CPES Q) (why/why not?) and enable people to adapt their lives to ‘new normal’. | - Comparison of average anxiety score with other eHNA data / average reduction in anxiety score between 1st and 2nd HNA with other eHNA data? (eg London/Leeds) - Patient perspective (Patient survey questions: eg Did you have a conversation about your needs and a care plan Y/N – if) | - eHNA data – number, type and severity of concerns - Patient survey, SSI |</p>
<table>
<thead>
<tr>
<th>2. Outcomes for health professionals</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2.1 Increased awareness and understanding of the life situation and what’s important to the individual / and can offer better support (eg as result of analysing HNA data, carrying out HNAs).</strong></td>
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</tr>
<tr>
<td>- How has HNA conversation and data influenced the way they understand needs of their patients and meet them? (MDT)</td>
<td>- How has HNA conversation and data influenced the way they understand needs of their patients and meet them? (MDT)</td>
</tr>
<tr>
<td>- Have they changed their service offer as a result / been able to influence service offer elsewhere?</td>
<td>- Have they changed their service offer as a result / been able to influence service offer elsewhere?</td>
</tr>
<tr>
<td>- Do they feel they can offer /signpost to better support? (eg where to refer/signpost – why /why not?) (MDT)</td>
<td>- Do they feel they can offer /signpost to better support? (eg where to refer/signpost – why /why not?) (MDT)</td>
</tr>
<tr>
<td>- Do community based services feel better able to tailor support and respond to their population as a result of doing HNA and CP?</td>
<td>- Do community based services feel better able to tailor support and respond to their population as a result of doing HNA and CP?</td>
</tr>
<tr>
<td><strong>2.2 Increased skills and confidence around providing care for people with cancer and identifying and discussing holistic needs, including confidence and knowledge of the model of assessing and meeting needs (hub function).</strong></td>
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</tr>
<tr>
<td>- How has training (and practice) of HNA and CP built their skills and competencies (and confidence)</td>
<td>- How has training (and practice) of HNA and CP built their skills and competencies (and confidence)</td>
</tr>
<tr>
<td>- How has content of HNAs and Care Plans changed over time (pre/post training and with practice)?</td>
<td>- How has content of HNAs and Care Plans changed over time (pre/post training and with practice)?</td>
</tr>
<tr>
<td>- Pre and post evaluation of training (training follow up FGDs)</td>
<td>- Pre and post evaluation of training (training follow up FGDs)</td>
</tr>
<tr>
<td>- Analysis of HNAs/CPs over time</td>
<td>- Analysis of HNAs/CPs over time</td>
</tr>
<tr>
<td><strong>2.3 Knowledge and relationships with support services.</strong></td>
<td><strong>2.3 Knowledge and relationships with support services.</strong></td>
</tr>
<tr>
<td>- Do they feel the HNA and CP experience and knowledge and relationship with support services, has made them more confident to risk stratify appropriately (confident to stratify non face-to-face follow-up)?</td>
<td>- Do they feel the HNA and CP experience and knowledge and relationship with support services, has made them more confident to risk stratify appropriately (confident to stratify non face-to-face follow-up)?</td>
</tr>
<tr>
<td>- What is it that builds confidence / (or not) with support services (relationships, trust)?</td>
<td>- What is it that builds confidence / (or not) with support services (relationships, trust)?</td>
</tr>
</tbody>
</table>
| 2.4 Increased satisfaction through improved care delivery (picking up recurrence, CoT, etc.) increased sense of resilience for teams (reduced sense of burden – patients more activated) | How has HP (CNSs) perception of their satisfaction, resilience etc changed with implementation of HNA and care planning (introduction of support workers, training on HNA etc)? | SSIs/FGDs with each CNS team  
Pre and post evaluation of training (training follow up FGDs) |
<table>
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<tbody>
<tr>
<td>3. Outcomes for the system</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 3.1 Better communication with patient and across system | Have patients been offered copy of Care Plan?  
Have patients been offered a TS – was it explained to them and by whom? Did they understand it?  
Were TSs received and understood by primary care? Did they take any actions as a result – eg use in conversation/CCR?  
Have community providers and PC received care plans? What have they done with them – ie reviewed actions? | Patient survey  
And longitudinal cohort SSI  
CPES – Q55 But NB perception of ‘Care Plan’  
Record of TS sent out  
Potential to use GP survey done in Barnsley. |
| 3.2 Better coordination of care across secondary, primary and community care system (N) | (unnecessary is hypothesis behind risk stratification – eg unnecessary consultant follow-up appointment) | Data on stratified follow-up?  
Comparison of patients attending consultant led follow-up (taking into account underlying denominator diagnoses)  
(There is some understanding of Risk Stratified Pathway baseline. CCG data on numbers of community follow-up – tells you how many in hospital. Different types of risk stratified follow up as per guidance and NHSE metrics: Denominator number of 1st treatments, then % of….  
○ Personalised stratification to self- |
| 3.4 Reduction in unplanned service use across all settings e.g. emergency presentations, GP appointment, hospital admissions (N) | management follow up  
| o Personalised stratification to face to face follow up  
| o Other (eg: straight to Palliative Care, complex tertiary referrals) | Audit work of Primary Care (GP) attendance following diagnosis? link with HNA & CP.  
| Patient cohort SSI tracking (qualitative)  
| Possibly comparison of cancer patients attending GP appointments between years if the above shows differences (interrupted time series)  
| Acute oncology service – cancer patients presenting in unplanned way?  
| Patient survey – what would you have done? |

| 3.5 More proactive system response and planning based on improved understanding of need | How have we been more proactive with individual patient care? (eg more rapid response, early intervention before crisis, individuals know where to go if they have problems)  
| How has system been more proactive (eg have we provided rapid entry point back in to system (avoiding A&E) – risk stratified / not?  
| Has HNA data on needs informed (see HP question above) service offer (eg group clinics, timing)?  
| What has changed as a result (i) service planning, (ii) commissioning (iii) delivery - utilisation of existing services, new services, have services ceased? | Pathway changes, service offer changes, with rapid re-entry (to GP/to CNS/to CSW/community support) – comparing risk stratified to non-risk stratified, discharged to non-discharged  
| % proportion of HNA concerns and needs and reduced severity, addressed  
| Patient cohort – tracking – what did they do and why/ what would they have done? What were they told to do? |
| 3.6 Better communication between acute and primary care means that GPs and practice nurses have better understanding of their patients' treatment and ongoing needs. (esp. CCR,TS) (N) | See 3.2 above  
- (Did GPs /practice nurses receive TSs and Care Plans, did they understand them, did they increase their understanding of patients' needs and how did they use them?)  
- Did enhanced CCRs result in better understanding of patients' needs? | Workforce – CNS/acute and GP/practice nurse survey |

Notes: Patient survey might be standard survey across all sites and/or standard questions in respective satisfaction surveys
Glossary

Cancer Alliance
Cancer Alliances are a way to bring together local senior clinical and managerial leaders representing the whole cancer patient pathway across a specific geography.

Together with the National Cancer Vanguard, they led the local delivery of the Independent Cancer Taskforce’s ambitions for improving services, care and outcomes for everyone with cancer⁴³.

Allied Health Professional
Allied health encompasses a broad group of health professionals who use scientific principles and evidence-based practice for the diagnosis, evaluation and treatment of acute and chronic diseases; promote disease prevention and wellness for optimum health, and apply administration and management skills to support health care systems in a variety of settings⁴⁴. In a cancer setting the most used professionals include physiotherapists, occupational therapists, dietitians and speech and language therapists.

Cancer Rehabilitation
There are four recognised stages of cancer rehabilitation, which illustrate how rehabilitation spans the entire treatment pathway contributing to a range of positive outcomes. These are:
• Preventative: reducing impact of expected disabilities and improving coping strategies
• Restorative: returning an individual to pre-morbid levels of function
• Supportive: in the presence of persistent disease and need for treatment, rehabilitation is aimed at limiting functional loss and providing support
• Palliative: prevents further loss of function, measures are put in place to eliminate or reduce complications and to provide symptom management⁴⁵

Cancer Care Review
Is a discussion between a patient and their GP or practice nurse about their cancer. 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-management⁴².

Clinical Nurse Specialist (cancer)
Registered nurses, who have graduate level nursing preparation and who would usually be expected to be prepared at Master’s level. They are clinical experts in evidence-based nursing practice within a specialty area. The specialty may be focused on a population (e.g. young people), type of care (e.g. palliative care), type of problem (e.g. lymphoedema), type of treatment (e.g. chemotherapy) or tumour type (e.g. lung cancer)⁴⁷.

https://www.england.nhs.uk/cancer/strategy/alliance-guidance/
⁴⁴ Association of Schools of Allied Health Professionals (2018) Definition Of Allied Health http://www.asahp.org/what-is/
⁴⁷ National Cancer Action Team (2010) Quality in Nursing Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist
Health Inequality and Inequity
Can be defined as differences in health status or in the distribution of health determinants between different population groups\(^{48}\).

Holistic Needs Assessment
An HNA is a simple questionnaire that is completed by a person affected by cancer. It allows them to highlight the most important issues to them at that time, and this can inform the development of a care and support plan with their nurse or key worker. The questionnaire can be completed on paper, or electronically\(^{46}\).

Health and Well-being Event (H&WB) (or clinic)
An education and support event to prepare the person for the transition to supported self-management. The event should include advice on the relevant consequences of treatment and the recognition of issues, as well as details of who to contact. It should also provide information and support about work and finance, healthy lifestyles and physical activity\(^{46}\).

Improving Access to Psychological Therapies
Improving Access to Psychological Therapies (IAPT) is an NHS programme rolling out services across England offering interventions approved by the National Institute of Health and Clinical Excellence (NICE) for treating people with depression and anxiety disorders\(^{49}\).

Integrated Care
Integrated care is an organising principle for care delivery with the aim of achieving improved patient care through better coordination of services provided. Integration is the combined set of methods, processes and models that seek to bring about this improved coordination of care\(^{50}\). Integration can be between physical and mental health, acute and community care or health and social care.

Integrated Care Systems
In 2016, NHS organisations and local councils came together to form 44 Sustainability and Transformation Partnerships (STPs) covering the whole of England, and set out their proposals to improve health and care for patients. In some areas, the partnership evolved to form an Integrated Care System, a new type of even closer collaboration.

In an Integrated Care System, NHS organisations, in partnership with local councils and others, take collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve.


Local services can provide better and more joined-up care for patients when different organisations work together in this way. For staff, improved collaboration can help to make it easier to work with colleagues from other organisations. And systems can better understand data about local people’s health, allowing them to provide care that is tailored to individual needs.

By working alongside councils, and drawing on the expertise of others such as local charities and community groups, the NHS can help people to live healthier lives for longer, and to stay out of hospital when they do not need to be there.

In return, Integrated Care System leaders gain greater freedoms to manage the operational and financial performance of services in their area.

**Long Term Condition**

Long-Term Conditions or chronic diseases are conditions for which there is currently no cure, and which are managed with drugs and other treatment, for example: cancer, diabetes, chronic obstructive pulmonary disease, arthritis and hypertension.\(^51\)

**Living With and Beyond Cancer**

Looks at the whole patient pathway from start of diagnosis to surviving and living with cancer as a long term condition.

**Macmillan Badged**

Badging refers to a post that through mutual agreement has either (a) previously been funded by Macmillan or (b) been adopted by Macmillan. More information can be found through the Macmillan website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

**Multidisciplinary Team**

A multidisciplinary team is a group of health care workers who are members of different disciplines (professions e.g. psychiatrists, social workers, etc.), each providing specific services to the patient.\(^52\)

**Mental Health**

Mental health is defined as a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.\(^53\)

**Mental health problems**

Mental health problems affect around one in four people in any given year. They range from common problems, such as depression and anxiety, to rarer problems such as schizophrenia and bipolar disorder.\(^54\)

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\(^{52}\) Health Service Executive V2 (2017) Multi-disciplinary team [https://www.hse.ie/eng/services/list/4/Mental_Health_Services/dsc/communityservices/Multidisciplinaryteam.html](https://www.hse.ie/eng/services/list/4/Mental_Health_Services/dsc/communityservices/Multidisciplinaryteam.html)


Prehabilitation
Prehabilitation is typically viewed as the beginning of the continuum of rehabilitation and occurs from the time of diagnosis to the point of receiving treatment for their cancer. The aim is to optimise patients' health, reduce the incidence and the severity of current and future impairments resulting from cancer treatment.

Recovery Package
The Recovery Package is a series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer.

These include:
- A holistic needs assessment (HNA)
- A Treatment Summary
- Cancer Care Reviews (CCR) (conducted in Primary Care)
- A health and well-being event

Treatment Summary
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.

The Treatment Summary aims to inform the GP and other primary care professionals of actions that need to be taken and who to contact with any questions or concerns for longer term management. The person affected by cancer also receives a copy to improve their understanding and to know if there is anything to look out for during their recovery.

References

26. Macmillan Cancer Support (2017) Am I meant to be okay now?
34. NCRI (2018) UK Top 10 Living With and Beyond Cancer research priorities – https://www.ncri.org.uk/lwbc/
42. Association of Schools of Allied Health Professionals (2018) Definition Of Allied Health http://www.asahp.org/what-is/
   http://www.who.int/features/factfiles/mental_health/en/
