These are working documents that were developed as a resource for design and evaluation of Macmillan’s support to Recovery Package implementation, but others are welcome to draw on them. The content is being tested and may be revised over time.
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The Recovery Package – definition of the core

The purpose of defining the core

A common description of the Recovery Package – what it does, how it works and for whom

As explained in the Introductory Note, these definitions and the Outcomes Framework can be used for two purposes:

1) to support the design and planning of Recovery Package interventions, and

2) to develop appropriate measures for regular routine data collection and deeper dive evaluation.

Defining the core is essential ground work for developing a valuable Measurement Framework. The Measurement Framework includes key questions which should be asked across all Recovery Package interventions as well as suggested measures to help answer those questions.

This document provides an explanation of how the core should work across contexts and it also outlines some areas of good practice. The contents of this document have been used to inform what routine data (through monitoring) is needed to understand if the core is working in the way that is expected. It also highlights gaps in knowledge where further exploration is required (through evaluation).

Gathering this information will help to:

a) develop knowledge and confidence on if, how and why the Recovery Package works in different contexts and settings, and

b) continuously improve current Recovery Package interventions by using the relevant evidence and insight to design more effective interventions.

These definitions of the core have been signed off by the Recovery Package Task and Finish Group in Macmillan. However, it is recognised that there are variations in how the Recovery Package is delivered which cannot be fully explored in this document. There are new models being developed (eg, the Local Authority Partnership programme) and implemented (eg, Improving Cancer Journeys) where identification of holistic needs and navigation to the right information and support is based in community settings. As we collect more evidence about these new models this description of the Recovery Package will be refined to reflect the new knowledge and learning. This is a longer-term learning objective and, at the earliest, refinement could take place in the latter part of 2018. This is Version 4 of this document. After we have collected the relevant data, analysed, interpreted and learned from it, we will develop Version 5. See Appendix 2 for an illustration of how we will further define and/or redefine the Recovery Package.
How this document was developed

These definitions have been developed from collated knowledge in the Portfolio of Interventions Recovery Package blueprint, a review of the available evidence of outcome delivery from Recovery Package evaluations, a broader evidence base (both Recovery Package specific and Recovery Package non-specific), and perspectives from internal Macmillan colleagues and external colleagues.

The people involved

In 2017, there were two workshops based in Macmillan’s London offices and two workshops in Birmingham which focused on defining the core and developing the Outcomes Framework. A fifth workshop in Birmingham focused on developing key questions to inform the Measurement Framework. The Evidence Team (Natalie Dale and Claire Burley) have led these workshops with support from the Evaluation and Impact Team. The dates of the workshops and a list of those colleagues who attended can be found in Appendix 1. Their expertise and commitment have been fundamental to developing this document. Also, colleagues both internal and external, have supported the development of this document and the Outcomes Framework through document reviews. Their contribution has been valuable in further refining the documents.

The Introductory Note, refers to the plan for testing Evidence Outputs in 2018. As the outputs are tested, there will be wider consultation with people living with and affected by cancer to further refine and develop this work.

A note on context

This document explains what the Recovery Package is, what it does and how we expect it to work across contexts and settings. This is to support consistent and aligned design and measurement across the UK. This document does not explain the enablers, barriers, opportunities and challenges across contexts and settings in any depth. This is because it would make the definitions too broad and the document too long. However, this does not mean context will be ignored. On the contrary, it will play a prominent and essential part in the Outcomes and Measurement Framework which we plan to learn from.

As Macmillan and partners pilot the Measurement Framework in 2018 (see the Introductory Note for more details), we will be collecting, analysing and interpreting data to give a clearer picture of the variations in implementation. Together with findings from our evaluations (deeper dive analysis) we will have more evidence on effectiveness, common challenges, barriers, enablers and opportunities across different contexts and settings in the UK. This is a longer-term learning plan.

The Outcomes Framework outlines common key assumptions that are important for effective implementation. Similarly, in the description of how we expect the components to work in this document, see pages 14, 19 and 23, the common assumptions need to be explored in design and monitored in implementation.
It is also important to draw on the learning already available. Common barriers and challenges to implementing Macmillan-funded interventions are well documented in the internal Learning Reports. Common themes include:

a) System change (including behavioural change and organisational change) takes considerable time, effort and commitment, which cannot be underestimated in design and implementation.

b) Programme alignment with local, regional and national priorities is crucial for buy in.

c) Stakeholder engagement is time consuming but can function as a key driver of change.

Many of the themes outlined in the Learning Reports are applicable to Recovery Package design and implementation, as well as to specific challenges, such as:

a) Variations in effective communication and coordination in secondary care.

b) Variations in effective communication and coordination from secondary care to primary care.

c) Disjointed IT systems across the treatment pathway so that patient information cannot be shared efficiently and effectively (and, in some cases, cannot be shared at all).

d) High levels of staff turnover and strained resources affecting the capacity of teams.

Carers

The impact the Recovery Package has on carers is not explicitly addressed in this document. However, the assumption is that because the Recovery Package provides personalised care and support and aims to improve the experiences of people living with cancer, then it will have a positive impact on carers too.

What difference does the Recovery Package seek to make?

The Recovery Package was initially conceived as a person-centred approach to enabling recovery. It gives a framework for supportive interventions which, when effectively combined, support people’s recovery.

Ultimately, the Recovery Package seeks to provide the support that people living with cancer need to lead their best possible lives. It aims to contribute towards improved quality of life, improved health outcomes and improved experience of care and support.

More specifically, the Recovery Package aims to ensure that, from diagnosis or soon after, people’s needs are identified and addressed so that their care is person-centred and their health and wellbeing needs are recognised and supported. To achieve this, there is a need for the health and social care system to work in an integrated way. Effective communication and coordination across primary, secondary and community settings are vital to achieving this end.
People diagnosed with cancer will need to understand what they are entitled to from the health and social care system, and how they can access and re-access the right information, support, and care. A more detailed description of the specific outcomes we want the Recovery Package to deliver or contribute towards are outlined in our Outcomes Framework. These outcomes are categorised by:

• the individual living with cancer,

• professionals working in primary, secondary and community settings who are involved in the individual’s care and support, and

• the health and social care system.

(Please note, professionals can be registered or unregistered – we are seeking to influence system-wide professionals.)
The Core Components of the Recovery Package
Holistic Needs Assessments (HNAs) and Care Planning

The problem we aim to solve

People diagnosed with cancer and moving through the treatment pathway experience inconsistencies in having their needs identified and met. Evidence suggests that after diagnosis people have unmet needs which change across their treatment pathway, and through short and long-term recovery. Common concerns and needs include worry, fear, anxiety, fatigue and fear of recurrence.

The solution

If we provide people with the opportunity to identify and address their holistic needs across the treatment pathway and beyond then they are more likely to experience person-centred care and support. It is recognised within the health care sector that HNAs and Care Planning are important parts of overall care and they should be considered at different times across the pathway.

What

The HNA is a structured method of identifying needs and discussing and agreeing the best way to meet them from the person’s perspective. It involves identifying and prioritising needs and then planning to address the prioritised needs. It offers a way to consider the multi-dimensional effect of cancer and its treatment. The HNA is a way to engage with the person and address their concerns and/or needs at the most appropriate times.

Care Planning is an integral part of addressing concerns and/or needs. A care plan records the needs that are most important to that person at that time. It should be shared with the person and other health and social care professionals so the plans can be enacted. It also provides the foundation for future re-assessment and re-planning as a person’s holistic needs can change along the pathway.

Every formal HNA should result in a care plan that summarises the issues and concerns identified as a priority for the person. It should also record the goals, actions and approaches jointly agreed to address them. This should include documentation of any issues or concerns that were felt to be addressed immediately through the assessment as well as any actions to be taken by the person (eg, follow-up signposting) or the professional (eg, referrals to support services) after the assessment. It should be developed in partnership with the person, and the

2. Ibid
person should hold their HNA and care plan so that they can share it with their carers, family and friends if they wish. Reviewing the content in the care plan (eg, when conducting audits) can give an indication of whether the HNA and Care Planning was good quality (rather than simply tick box exercises). Patients should also be asked for feedback as to how useful or valuable they find the process. Together, this can give professionals confidence in the quality and effectiveness of HNAs and Care Planning.

### For whom

All people living with cancer should be offered the opportunity to talk through their concerns and needs and make plans to address them. This includes people who may have more complex needs, those who are receiving palliative care, and those at the end of life.

How the assessments and planning are approached – and what they look like – will vary from person to person. The extent to which the assessments and planning will support people to self-manage (with supported self-management being an important outcome for some people) will also vary. This will likely depend on many factors including their:

- type and stage of cancer,
- co-morbidities and long-term conditions,
- life situation and support network, and
- resilience.

However, the intention is to give the most appropriate level of support to all people. This supports an individual to self-manage to a personally suitable degree.

There is a need to gather the relevant information to understand the extent to which HNAs and Care Planning affect different people and whether significant patterns exist. As a starting point, more systematic collection of data is necessary in order to answer the following questions:

1) Who is offered an HNA and Care Planning (and why)?
2) Who is not offered an HNA and Care Planning (and why not)?
3) Who takes up HNAs and Care Planning (and why)?
4) Who does not take up HNAs and Care Planning (and why not)?

(Please note, ‘and why’ or ‘and why not’ in brackets for each of the four questions above would be explored in evaluation rather than in routine data collection.)

These questions have been included in the Measurement Framework with suggested measures to help answer them. Also included are suggestions on the demographic and clinical data to collect to support the analysis of patterns in terms of who is offered HNAs (or not) and who up takes HNAs (or not). There is also room for flexibility when it comes to gathering additional relevant local data that can further inform these questions. This ‘for whom’ data can be used across all components of the Recovery Package.
Differences from person to person
Some people’s concerns and needs may be resolved as part of the assessment process itself (e.g., providing further information, prescribing medication, or low-level emotional support from simply talking things through) or from a further conversation later. Evidence demonstrates that when people are given the opportunity to identify their needs, a significant percentage of those people have their needs addressed immediately and no further action is required at that time.

Other people’s concerns and needs will be resolved through the person taking responsibility for further action in relation to self-care and self-referral. For example, they might become more socially active again, obtain further information, speak to their partner, attend a support group, or undertake more physical activity.

However, for some people, their concerns and needs may not be resolved through the above actions and they will need extra support. This may require a referral to another service or help with navigating to the appropriate sources of information and support. For those people that have very complex needs, those in palliative care or those at the end of life, the options for self-managing and taking action will be challenging.

However, it is still valuable to offer HNAs and Care Planning to support a better experience and person-centred care during a difficult time.

Links to stratified pathways
Conducting HNAs and care plans can also inform decisions about which people are more suited to stratified pathways. For example, while a person may be classified as ‘low risk’ clinically, if they lack social support and networks this may mean they will still require more intensive support. In this kind of situation, the HNA and care plan function as necessary triangulation tools for stratification by helping to uncover the level of intensity of support a person requires.3

When
Holistic needs do not stay static. HNAs and Care Planning should happen fluidly across the pathway. Ideally it should be instigated when the person needs it by either the professional or the person themselves. It is doubtful that this is current customary practice. As a minimum at least two HNAs should be offered:

1) as soon after diagnosis as possible and appropriate, and before treatment begins, and

2) around the end of active treatment and prior to the transition back to primary care.

These expectations align with some regional measurement guidelines on the Recovery Package. They stipulate that the first HNA should be conducted within 31 days after diagnosis and the second HNA should be conducted six weeks after treatment ends. The difference between the Measurement Framework developed by Macmillan is that it is focused on quantifying:

1) the characteristics of people that are offered HNAs (and those who are not offered HNAs), and

2) the characteristics of people that take up the offer of an HNA (and those who do not take up the offer).
(Please note, the characteristics of people are determined by demographic clinical data and the appropriate local data – see the ‘For whom’ section on page 9. Also, the Measurement Framework does use the timeframes of 31 days and six weeks for consistency.)

By collecting this information, we will gain more insight into optimal times for HNAs and Care Planning for different people in different circumstances. This may include people who receive a late diagnosis when there has been no previous treatment, people who it has been decided will not receive treatment, and people where treatment will be ongoing, eg, blood cancers.

We do need a better understanding of if, how and when different settings offer HNAs and Care Planning at the most appropriate times. For example, if a person does not request it, we need to make sure the system offers it based on the points in the pathway that we know are often most meaningful and beneficial to people.

Recovery Package programmes across the UK will want to further explore and understand when the most meaningful points are for HNAs and Care Planning from the perspective of professionals and people affected by cancer in those localities. We can then consider our expectations in relation to the local system perspective on the most ‘natural’ points for aligning HNAs and Care Planning with existing practice. We can also think about what might need to change if there is no alignment. There are questions and suggested measures in the evaluation section of the Measurement Framework to further explore this.

It can be challenging to pinpoint when HNAs and Care Planning are done across the pathway. This can be due to people moving from one setting to another soon after diagnosis. For example, a person may move care settings just after diagnosis and so secondary care (or the setting in which they were diagnosed) may lose the opportunity to do an HNA soon after diagnosis (if that is the right time for the person). It is then difficult to know if that person will have an HNA and care plan in the setting they move to. If it is not customary practice to do HNAs and Care Planning in the health and social care settings that people move through, then it is harder to ensure they are carried out at the optimal times for the individual.

To help address this challenge it is important that those working in the health and social care system proactively communicate to people living with cancer and their carers about how valuable HNAs and Care Planning can be and when and where they can have them. They can then use that knowledge to access and re-access the necessary services and support which facilitates self-efficacy and the confidence to self-manage to a personally suitable degree.

Proactive and targeted communication about what is on offer and why it is in the form of the Recovery Package is also important because there is often a plethora of information given to the individual at and after diagnosis. Too much information can be overwhelming. This information can be in the form of leaflets, information sheets, booklets, clinical letters, appointment letters, blood test results and clinical staff business cards. Many people at diagnosis feel overloaded with the amount of information they need to digest. Therefore, proactive, targeted communication, which could be in the form of prompts and reminders for HNAs and Care Planning, are important enablers for the uptake of HNAs and Care Planning. Questions to further explore communication are included in the evaluation section of the Measurement Framework.
Who does it and where

There are variations as to who would facilitate HNAs and Care Planning and in what settings. In some cases, for example, HNAs might happen in a social care or a community setting.

Whichever setting the HNA and Care Planning is conducted in, the consensus in workshops 2, 3 and 4 (see Appendix 1 for those present) was that it needs to be facilitated by a person with the necessary skills and competencies. There was also a consensus that the HNA and Care Planning is an essential early step (not necessarily the first step) after diagnosis. Although HNAs and Care Planning are structured, facilitated discussions to identify and prioritise a person’s holistic needs, prior thought and preparation before the conversation can be effective. For example, the eHNAs concerns checklist can be completed by the individual before meeting with health or social care professionals. The person then has had time to think through their needs and concerns, laying the groundwork for a more informed conversation. The conversation can also take place during the development of the care plan depending on whether the HNA and planning are carried out together or in one session or separately.

It is important to note that the conversation does not necessarily have to be face to face, although face-to-face conversations are likely to be preferable for most people. However, other media can be used to have that conversation in real time (e.g., over the phone, via Skype or online). The conversation should be between the person living with cancer and a health or social care professional or someone with the capability and skills to support the person to explore their needs and concerns and ways to meet them. There are, and will be opportunities to have these conversations and interactions using digital technology.

To capture the variations in who does HNAs and how, we can say that:

It is a structured, person-centred conversation, interaction or dialogue, in real time, between a person who has cancer and the relevant professional. That professional can be registered or unregistered but they must have the capability and skills to support the person to identify their holistic needs, prioritise them, and facilitate addressing those needs.

(Please note, in some circumstances the conversation, interaction or dialogue can be facilitated by a trained volunteer working in a relevant team.)

This real-time interaction must:

• be focussed on what the person wants to discuss,

• identify what is most important to the person from a range of holistic domains – not just the clinical one – and

• discuss and agree how to address needs in a way that is most meaningful to the person, and assign responsibility between the professional and the person for follow-up actions.
Tools and resources

As stated previously, HNAs and Care Planning are structured methods for identifying and addressing holistic needs. There are various useful approaches and tools that can be used to promote and facilitate the quality. The best approaches and tools are those that provide a structure to the assessment. This structure should ensure that the focus is on considering a full range of holistic needs and prioritising those that the person themselves feel are most important, rather than the professional. For example, the Concerns Checklist tool, Washington Quality of Life tool (UW-QoL), the Distress Thermometer, the Sheffield Profile for Assessment and Referral for Care (SPARC) and Motivational Interviewing (MI). Some of the tools (eg, The Distress Thermometer, Macmillan’s Concerns Checklist, and SPARC tool) can support people to self-assess which then becomes a useful input to an assessment conversation.

How we expect the HNA and Care Planning to work

Although the following description of the HNA and Care Planning is relatively linear in structure, it aims to give an overview of how we expect them to work across different contexts and the assumptions (the ‘and’ statements) that we are making (which should be monitored in work going forward). This logic assumes that an initial conversation, interaction or dialogue should happen early on (as close as possible to diagnosis) and in real time.
If people are offered a way to explore their holistic needs as early as possible after diagnosis through a guided conversation, interaction or dialogue with a relevant professional in real time (actions done) and the relevant professional sees facilitating that conversation as their role and responsibility, and is confident that they have the skills, capability, time and resources to do so (assumptions) and the person living with cancer trusts their professional so they can talk openly and honestly, sees the value of identifying their holistic needs, and is able to articulate their needs at the time of the conversation (assumptions) then people will have a conversation about what matters to them and holistic needs will be understood by the professional and met either through that conversation or subsequent actions, goals or approaches that are agreed and documented within the care plan (outcome/change we want to see).

If there is a record of how holistic needs have been addressed through the assessment process (eg, through information, advice, reassurance, or knowledge shared during the conversation) and/or how needs will be addressed in the future, (eg, through referrals to be made and/or self-management action to be taken) (output) and the relevant professional reflects back the conversation, the needs that have been identified, and the actions that have been or will be taken in a clear way (assumptions) and the person living with cancer, and/or those who support that person, have absorbed the information (assumptions) then the person and the professional will be confident that needs have either been addressed at that time or will be addressed through further actions (outcome/change we want to see).

If care plans are sent to and accessed by the relevant people involved in a person’s care across primary, secondary, and community settings, and signposting, navigation and referrals are made at the right times (actions done) and the relevant professionals involved in that person’s care understand it, provide the relevant care and support, have knowledge of suitable and appropriate services and/or sources of information to refer to, and have the time and resources to refer and direct people (assumptions) and the relevant sources of care and support are available (assumptions) and people are able and willing to communicate their planned actions (assumptions) then the relevant professionals involved in that person’s care will understand the actions that have already been taken and the actions that are planned to be taken, which will ensure continuity across settings. Care plans will be coordinated and actioned effectively across settings to address the needs of people at that point in time (outcome/change we want to see).
A consistent holistic needs framework

Holistic needs
Macmillan and partners need a consistent common framework for holistic needs. We could adapt the existing recognised ‘Holistic Framework’ models that are used in health and social care, so we are using a framework that is widely recognised. The recognised framework contains five main domains (with sub domains within each):

• practical,
• physical,
• social,
• psychological and emotional, and
• spiritual.

We also have definitions for Macmillan’s times of need, which could be integrated or form sub-sections of the overall framework. We do not want to be prescriptive about the use of Macmillan’s ‘Concerns Checklist’ tool. However, to make it more appealing and relevant to health and social care professionals we can articulate how the checklist, formats and templates for Care Planning align with a common ‘Holistic Framework’.
Treatment Summaries
Communicating and coordinating information about treatment intent and the potential late side effects of treatment

The problem we aim to solve

The consistency of post-treatment support given by primary care is varied. People struggle with how to manage post treatment, how to cope with the side effects resulting from treatment (these are sometimes called ‘consequences of treatment’ or ‘late effects of treatment’) and how to cope with the impact cancer can have on their lives. This is often due, in part, to a lack of clear communication and relevant information exchange between secondary and primary care settings and the person themselves.

The information shared by secondary care in summary notes or discharge letters – particularly from oncology – does not always clearly define what primary care needs to know in order to offer adequate support. A summary of oncology treatment is not always targeted or relevant enough for the GP to be clear about their role in monitoring and supporting the person. This can create a barrier between the GP and the person living with cancer and prevent them from having informed discussions about ongoing care needs and the potential consequences of treatment. It also makes it difficult for primary care to identify their role in post-treatment support and monitoring, particularly around consequences of treatment and symptoms that require rapid reassessment in order to identify a recurrence.

The solution

Clear and consistent information about treatment and any potential consequences of treatment is needed. Timely information on the early identification and management of reoccurrence, and on how to monitor and manage post treatment should be provided to both primary care and the person who has completed treatment. This should occur after each phase of treatment if the person is having more than one treatment modality.

This information should include a summary of the treatment received and the treatment aim, everything the person has been told about their prognosis (eg, whether it is curative or palliative), an ongoing management plan in secondary care, recurrence alert symptoms, potential consequences of treatment, recommended actions for primary care, and a key contact in secondary care for any questions or concerns. Relevant READ codes for primary care are also important for coding within primary care IT Systems to allow for more automated alerts and accurate records when the person is reviewed by a GP or other primary care professional. The person in treatment or finishing treatment also needs a record to support them in discussions with their relevant professional in primary care about clinical management and signs of reoccurrence.
**What**

A person should be offered support from primary care during and after treatment. To support this, primary and secondary care need to communicate effectively and there should be clear lines of responsibility and accountability in each setting along the treatment pathway and beyond. If relationships and communication between secondary care and primary care are established early, this supports a smoother transition from secondary to primary care once treatment is completed.

The responsibility of secondary care is to ensure that clear and comprehensive information is provided to primary care and the person being treated for cancer. This information should include:

- the treatment,
- any immediate to longer term effects (consequences) from the treatment that they need to be aware of,
- ongoing clinical management and monitoring, and by whom,
- any further actions that need to be taken by the person or by professionals, and
- who to contact in secondary care with any questions or concerns.

The responsibility of primary care and the individual is to ensure that:

- this information is understood both by the necessary primary care professionals and by the person undergoing treatment,
- the person living with cancer is aware of any actions they need to take to help them to manage their own care, and
- the Treatment Summary and other information, such as HNA’s and care plans, inform discussions between primary care professionals on how actions will be followed up.

The Treatment Summary is primarily an important communication tool which can be used in both primary and secondary care settings. It also serves as a record that the person and their professional can look back on and use to inform conversations. For this reason, a Treatment Summary (or the equivalent document that lays out treatment information and the possible consequences of that treatment, in a clear and structured way – from here on termed ‘or equivalent’), should always be offered to the person completing treatment, and should be in a format that they, as well as professionals, can understand.

People can often struggle when they are seen less in secondary care and, while the Treatment Summary is a communication tool for professionals, it is also an enabler for ongoing support. It allows primary care to have more informed, meaningful conversations post treatment.
When

A Treatment Summary (or equivalent) should be produced, at the end of each phase of active treatment (after primary treatment and any subsequent phases of treatment). A delay in sending the Treatment Summary (or equivalent) to primary care informing them of diagnosis and treatments can result in a lack of appropriate support as the GP and primary care team may be unaware that the person has finished treatment.

Furthermore, the Treatment Summary (or equivalent) provides essential information to enable a more thorough and comprehensive Cancer Care Review in primary care. This Cancer Care Review should take place around the end of treatment (but can take place before) and is integral to a person’s support and care. A Cancer Care Review can also take place years after treatment comes to an end, but will still be informed by previous Treatment Summaries.

However, it is common for a Treatment Summary (or equivalent) not to be received by primary care. Therefore, the Cancer Care Review can be informed by other relevant information and communication from secondary care, such as an HNA, care plan or multidisciplinary team treatment discussion and plan (a MDT treatment summary discussion pre-treatment).

This information should enable timely support within primary care and ideally should empower the person to get the right support. Optimal times for the Treatment Summary (or equivalent) to be communicated to primary care and to be given to the individual could be:

- at the last post-treatment review appointment after treatment, or
- before the person is transferred to stratified care or long term follow up with longer intervals between touch points within secondary care.

These times will vary depending on treatment. For example, for surgery the post-operative review is up to six weeks post-surgery. However, for oncology treatments this last review timeframe can vary. National guidance advises that the patient should receive the Treatment Summary within six weeks of the end of their treatment. More needs to be understood about the mechanism of how and when the Treatment Summary typically lands in primary care and how triggering a Cancer Care Review works best in primary care. There are no prescriptive time frames in the Measurement Framework due to the complexity and variations in treatment, and questions for monitoring and evaluation are focused on exploring current practice in timings, patterns and examples of good practice.
Who does it and where

The Treatment Summary (or equivalent) is produced by secondary care. The relevant professional in either secondary or primary care can use this information to inform a conversation with a person about their treatment. Having this initial conversation about treatment with the person completing the treatment is probably best suited to secondary care in most circumstances. It may form part of a general post-treatment or discharge conversation, and it is important that all relevant information is shared, and that symptoms of recurrence and the potential consequences of treatment are highlighted during this discussion. A copy of the Treatment Summary should be given to the person finishing treatment so they can refer to it if they need to. However, as explained in the ‘what’ section above, it is the responsibility of secondary care to give clear and comprehensive information to primary care – not the responsibility of the person living with cancer.

Tools and resources

The Macmillan Treatment Summary template contains information that has been identified as helpful to GPs at the end of cancer treatment phases. It can supersede multiple forms of communication from secondary care that GPs might find unclear. It is a simple summary of a patient’s cancer diagnosis, treatment, and ongoing management plan. However, there are other tools and documents that will serve the same purpose, such as, discharge letters, which could include that information in a clear format. We do know of one example where the Treatment Summary has replaced the discharge letter, and other examples of where electronic templates have been developed in some areas. Producing these electronically can help multiple professionals to input into them.

How we expect the Treatment Summary to work

If secondary care and primary care professionals are committed to – and understand their respective responsibilities in – supporting someone after acute phases of treatment, and if the Treatment Summary is a clearly written synopsis of that person’s treatment and it includes symptoms of potential recurrence, potential consequences of treatment, ongoing clinical management and the follow-up plan (including intent of treatment), and it can be used effectively by primary care professionals and the individual to inform conversations (actions)

and the summary is understood by professionals and the person living with cancer (assumptions)

and it is read and understood by the right person involved in that person’s care (assumptions)

and the information contained in the Treatment Summary prompts specific actions, and the relevant information is recorded and appropriately coded by the GP so that it is contained in patient notes and is accessible by those involved in that person’s care (assumptions)

then GPs, other primary care professionals and the person living with cancer will understand the treatment follow up, the future effects of their treatment, and symptoms of recurrent cancer that they need to be aware of. This gives a good grounding for the GP and other primary care professionals to actively manage ongoing clinical issues, both physical and mental, and advise on active prevention or reduction of reoccurrence at the post treatment phase (outcome/change we want to see)
Cancer Care Review

The problem we aim to solve

Poor consistency and lack of joined-up care across care settings lead people to feel unsupported when treatment ends, and they moved from a secondary to a primary care setting for the bulk of their care and support. Primary care receives communication from secondary care about diagnosis and treatment, however, the timeliness, length, format and detail is not always helpful and relevant for primary care professionals. Primary care is more likely to be clear about their role if the information is targeted and relevant, rather than a lengthy summary of treatment. They also lack clear information about what other ongoing support is needed to offer personalised care.

The solution

To improve the information flow between acute settings and primary care regarding an individual’s holistic needs, care plans and treatment. A member of the primary care team should review issues important to the individual using the Treatment Summary and previous HNAs and care plans (if available) with the individual to understand if there are any reoccurring or emerging concerns. There should also be attention given to any symptoms that may signal recurrence, and the individual should be aware of the importance of a healthy lifestyle. Other information on local services and support should be given to the individual post treatment.

What

Cancer Care Reviews involve a person living with cancer having a conversation with a primary care healthcare professional about their needs in order to ‘raise any issues relating to their cancer or treatment that are impacting on their quality of life or wellbeing’. As previously stated, holistic needs for many people do not stay static from diagnosis, through and beyond treatment, and they may change significantly at different times in the pathway. To support people in the best possible way, ongoing, open conversations to identify and address changing holistic needs should be recognised as integral to person-centred care. Cancer Care Reviews offer a formal and structured way to have these types of conversations post treatment.

The Cancer Care Review incorporates both a clinical and non-clinical assessment of needs post treatment within primary care. The purpose of the Cancer Care Review is to identify the person’s holistic needs and to reassess the effect of cancer and its treatment on the totality of the person. It has a focus on all aspects of their life as they transition from treatment to follow-up and from secondary care to primary care. As such, the initial Cancer Care Review

conversation may have a focus on holistic needs, but consequences of treatment and symptoms of recurrence should also be discussed.

As with the HNA and Care Planning, an effective Cancer Care Review must involve a high-quality conversation which focuses on what matters most to the person with cancer at that time and it must give them an opportunity to discuss and explore any issues raised. The intensity and depth of the conversation will vary according to the individual’s changing holistic needs, their circumstances, and their treatment history.

As previously stated in the Treatment Summary section, ideally the initial Cancer Care Review should be informed by the Treatment Summary (or equivalent). A Cancer Care Review should include a review of:

- the person’s diagnosis and past treatments,
- previously documented conversations about identified needs, eg, referring to HNAs and care plans (if necessary and available),
- plans and actions to address needs, eg, referring to the care plan (if necessary and available), and
- what the person can do, such as adopt healthy lifestyle changes, and what support is needed to do it.

A Cancer Care Review is a thorough review of the above. There may be no more actions necessary, however new unmet needs may arise, and these should be addressed through subsequent HNAs and Care Planning.

As the Cancer Care Review, HNAs and Care Planning share many characteristics, the measures for all of them are similar in the Measurement Framework – with the obvious distinction of the additional medical information outlined in this section.

**When**

Guidance on when to conduct a Cancer Care Review varies, but it is generally between six and 12 months after diagnosis. Ideally, a person’s first Cancer Care Review appointment should take place when the person needs it, which can be prior to the end of treatment, or soon after. Timings will vary considerably depending on the person and their circumstances. However, offering a Cancer Care Review within six months of the end of treatment is a good general guideline. It is therefore problematic if a Treatment Summary (or equivalent) is provided or presented late.

There are examples of good practice of possible timings for a Cancer Care Review. For example, a Cancer Care Review can start with a phone call from primary care to the person shortly after diagnosis. This would be to check in with them and establish or develop the relationship. Also, this can be an appropriate time to identify concerns and check the person’s understanding of their treatment. This can then be followed by a dedicated appointment when active treatment is coming to an end or has finished. Some areas in the UK have now implemented annual reviews in line with other long-term conditions, ensuring that cancer-specific areas are addressed while recognising that cancer shares aspects with other long-term conditions and patients prefer holistically-delivered care reviews and Care Planning as opposed to a ‘disease silo’ approach.
As with HNAs and Care Planning, the Cancer Care Review is not a one-off post-treatment review. Cancer Care Reviews should be carried out as appropriate to monitor and address changing holistic needs, particularly as longer-term consequences of cancer or treatment emerge. The frequency of subsequent Cancer Care Review appointments can be planned at the initial Cancer Care Review, based on the issues and unmet needs identified.

**Who does it and where**

Cancer Care Reviews can be conducted by any healthcare professional working in primary care. Access to a person’s Treatment Summary (or equivalent) and previous HNAs and care plans support a Cancer Care Review. Although, in practice, Cancer Care Reviews do take place without all this information. Those professionals that facilitate the Cancer Care Review should have the capability to support the person to explore their needs and ways of ensuring that they can be met. Although the Cancer Care Reviews are predominantly coordinated within primary care, the holistic aspects of the review can be undertaken by professionals that sit in other settings, e.g., in community settings. Macmillan advises that a Cancer Care Review should be a face-to-face conversation.

The same definition that was used in the HNA and Care Planning sections can be used for the Cancer Care Review:

*It is a structured, person-centred conversation, interaction or dialogue, in real time, between a person who has cancer and the relevant professional. That professional can be registered or unregistered but they must have the capability and skills to support the person to identify their holistic needs, prioritise them, and facilitate addressing those needs.*

**Tools and resources**

The Macmillan Cancer Care Review template will shortly be available in all the main primary care IT systems and should be used as an aide-memoir to guide the Cancer Care Review conversation. Information and agreed actions need to be recorded in these templates to inform any future conversations with the person, and also to support future evaluation and data collection. Additionally, if READ coding is performed correctly and consistently, we will get a much better picture of people’s long-term needs relating to their treatment and recovery.
How we expect the Cancer Care Review to work?

As with the HNA and Care Planning, the Cancer Care Review supports the principle that if people are given the appropriate level of support for their situation at the right times, then they will develop the knowledge and skills to self-manage all or some aspects of their condition. As outlined in the HNA and Care Planning section, the level at which they will be able to self-manage will be dependent on their situation and resilience at different times across the pathway. Some people with cancer may be able to self-manage quickly after treatment, and others will need varying intensity of support at different times. Cancer Care Reviews are a method by which primary care teams identify what support is needed and either provide that support or refer on, or signpost appropriately.

If people are offered the opportunity to review and reassess their holistic needs (coordinated by primary care, although it can be done in other settings, such as in the community and coordinated by local authority), and medical needs are assessed by the relevant professional in primary care through a guided conversation (actions done)

and the relevant professional sees facilitating that conversation as their role and responsibility, and is confident that they have the skills, capability, time and resources to do so (assumptions)

and the person trusts their professional to talk openly and honestly, and sees the value of reviewing their holistic and medical needs (assumptions)

then people will have conversations about what matters to them, and holistic and medical needs will be understood by the professional so that further signposting to information and support and referrals can be actioned. This will ensure the right support for managing the consequences of treatment, spotting symptoms of recurrence and the practicalities to support improved health and wellbeing (outcome/change we want to see)
Health and Wellbeing information and support

The problem we aim to solve

People do not always have access to the kind of information and support that is specific to their needs across the treatment pathway. They are lacking information and education to understand the impact of healthier lifestyles in reducing their risk of recurrence and preventing or managing consequences of treatment both in the immediate and long term. They also lack knowledge on how to manage aspects of their cancer when living with and recovering from cancer.

The solution

To provide education, information, support and signposting to enable people to understand how they can support themselves better. This includes access to local services to support them to have healthier lifestyles and to get information on the critical symptoms of recurrence or late effects of treatment. It also includes ensuring people know where to seek advice quickly. Health and Wellbeing support through events also connects people who may be experiencing the same issues, allowing them access to peer support and support groups.

The Recovery Package seeks to address holistic needs, to provide the most appropriate information and support at the right time(s) for an individual and to support people to manage the effect that cancer may have on their lives, including the consequences of treatment. In essence, it seeks to maximise health and wellbeing for people living with cancer (while equipping and supporting them to self-manage at a level that is right for them).

Health and Wellbeing promotion can be thought of as a ‘golden thread’ which runs through all elements of the Recovery Package.
The aims of Health and Wellbeing interventions are generally to:

- educate people on how to live well,
- inform people about where they can access the support they need,
- help people to cope with difficulties (e.g., stress, anxiety, and the consequences and late effects of treatment),
- provide targeted information to people, and
- provide opportunities for people and their carers to access peer support.

There is variation in how Health and Wellbeing information and support is delivered across the pathway. This can range from arranged events to dedicated support directories to guidance leaflets. Currently, innovation work in Macmillan is exploring different ways of providing this support, which could be through hubs and through different technologies. This will support us to address issues of sustainability for some trusts, institutions and organisations that may struggle with resourcing events.

The evaluation section of the Measurement Framework includes common wellbeing measures as indicators of what effect the ‘package’ has on improved wellbeing.
Health and Wellbeing Events (one way to provide information and support)

What

Supporting and improving a person’s health and wellbeing across the treatment pathway and beyond is an important aim of the Recovery Package. As outlined above, this can happen through effective implementation of HNAs and Care Planning, Treatment Summaries and Cancer Care Reviews.

As there has been a shift towards the importance of seeing and treating the person as a whole, and not just focusing on the disease, clinicians and support staff have increasingly more experience in signposting for holistic needs. There is therefore a question over whether Health and Wellbeing Events are an appropriate component of the Recovery Package or whether they should be re-conceptualised as Health and Wellbeing Information and Support. This would be a more general support provision that would run from diagnosis onwards and across the whole pathway. The initial impetus for Health and Wellbeing Events was to bring non-clinical support services to patients in the acute setting. This was because the clinicians and support staff in that setting were not, at that time, expected to have the knowledge to signpost effectively. Also, there was a shift towards integrating some aspects of clinical practice of cancer into primary settings.

However, presently, Health and Wellbeing Events are still common and valuable ways to offer support.

Macmillan defines a Health and Wellbeing Event as a ‘semi-structured education event that offers relevant support and information to people living with cancer in order to help them become more able to self-manage’. Health and Wellbeing Events aim to equip people living with cancer to ‘take control of and participate in their recovery, to receive necessary information, and to learn about positive lifestyle change’.

Who delivers and what information

The value of delivering Health and Wellbeing Events is that professionals from multiple disciplines come together with people living with cancer to have a conversation. The events are targeted information and support interventions offering people the opportunity to ask specific questions about their personal situations. People can get information on subjects including:

• diet,
• getting back to work,
• finances,
• physical activity,
• symptoms of recurrence,
• anxiety,
• the consequences of treatment and late effects,
• what to expect from follow up care in community, and
• social care support.


6. H&WB Events were originally conceived to support people living with long-term conditions and not exclusively those with cancer.
For whom

Health and Wellbeing Events are arguably for people who are on supported self-management pathways or who are likely to in the future. However, they are not exclusively for people on self-managed aftercare, as others can also benefit. For example, people who may not be ready for self-management and who may need that extra support to prepare, or people who need more intense support, but who are able and willing to manage some aspects of their cancer. In some cases, Health and Wellbeing Events form part of the care stratification process.

When

Support, advice and information on health and wellbeing should be offered from diagnosis, throughout the treatment pathway, into recovery, and in palliative and end of life care, so that people can self-manage all or some aspects of their cancer. They should also know what they can expect from the ‘system’ so that they are better equipped for their self-management. Health and Wellbeing Events are often thought of as one-off events that people attend at the end of their cancer treatment. However, Health and Wellbeing support (not necessarily as an event) should happen at regular intervals across cancer care and treatment and should be part of the cancer pathway in the same way as clinical interventions are. At a minimum, Health and Wellbeing information and support should be offered:

- during treatment,
- immediately post-treatment, and
- further post-treatment.

If the provision of Health and Wellbeing information and support is to become embedded as part of the cancer care pathway, gaining buy-in from clinicians is essential. As such, influencing work that promotes patients’ needs and rights to access this information and support across the pathway will be an essential part of programme design for the Recovery Package.

Where

Health and Wellbeing Events can be delivered across different stages of the pathway, in either primary, acute or community settings, as appropriate.

How

There is a lot of variability in how and where Health and Wellbeing Events are delivered, who delivers them and for which audiences. For example, Health and Wellbeing Events can be traditional events comprising of presentations, market stalls and/or one-to-one sessions. Alternatively they could comprise solely of market stalls or presentations, and they could be volunteer led or they could be assessment clinics.
They can be designed so that there is space and time to access generic information and education about living with cancer, as well as more specifically targeted information on tumour-specific issues (eg, the consequences of treatment and late effects). Health and Wellbeing Events which provide information and support on other long-term conditions may also be explored as, increasingly, people living with cancer are also living with other long-term conditions.

It is important to include ways for people to feedback on events to keep the timing, format and content of Health and Wellbeing Events aligned with what participants want from them (eg, wanting to hear more from people who have been through similar experiences). This feedback can also be used to inform pathway improvements (eg, people wanting more information earlier in the pathway). Developing the themes, content and structure of Health and Wellbeing Events (or other information and support platforms) could be designed around times of need, each of the three cancer groups, or different tumour sites.
Appendices
Appendix 1

Workshop 1
10 May 2017, UKO

Natalie Dale – Evaluation and Impact Lead
Claire Burley – Senior Evidence Manager, Strategic Knowledge
Dany Bell – Specialist Advisor, Treatment and Recovery
Sarah Allen – Evidence Officer, North and North West
Louise Petchey – Senior Policy Analyst
Richard Butler – Project Manager, Social Investment
Jane Derbyshire – Commissioning Support Programme Officer
Michael Lacquiere – Senior Strategic Analyst
Anna Williams – Evidence Officer, London
Carol Chapman – Lead Cancer Nurse, Bristol
Daniel Thomson – UCLH Primary Care Project Manager

Workshop 2
6 June 2017, UKO

Natalie Dale – Evaluation and Impact Lead
Claire Burley – Senior Evidence Manager, Strategic Knowledge
Sarah Allen – Evidence Officer, North and North West
Louise Petchey – Senior Policy Analyst
Richard Butler – Project Manager, Social Investment
Jane Derbyshire – Commissioning Support Programme Officer
Michael Lacquiere – Senior Strategic Analyst
Anna Williams – Evidence Officer, London

Workshop 3
5 July 2017, Birmingham

Natalie Dale – Evaluation and Impact Lead
Claire Burley – Senior Evidence Manager, Strategic Knowledge
Dany Bell – Specialist Advisor, Treatment and Recovery
Sarah Allen – Evidence Officer, North and North West
Colm Burns – Evidence Officer, Northern Ireland
Kelly Shiell-Davis – Senior Evidence Officer, UK
Louise Petchey – Senior Policy Analyst
Nancy Whittaker – Strategic Partnership Manager, North West
Steve Edwards – Programme Manager, North
Liz Henderson – Special Advisor, System Redesign
Trisha Hatt – Strategic Partnership Manager, Scotland
Emma Frost – Engagement and Volunteering Manager, South East
Amanda Watson – Project Manager, Electronic HNA
Barry Keenan – Project Manager, London
Elaine Wilson – Strategic Partnership Manager, Midlands
Eric Davies – Programme Manager, Midlands
Workshop 4
19 July 2017, Birmingham

**Natalie Dale** – Evaluation and Impact Lead

**Claire Burley** – Senior Evidence Manager, Strategic Knowledge

**Colm Burns** – Evidence Officer, Northern Ireland

**Kelly Shiell-Davis** – Senior Evidence Officer, UK

**Louise Petchey** – Senior Policy Analyst

**Anna Williams** – Evidence Officer, London

**Nancy Whittaker** – Strategic Partnership Manager, North West

**Steve Edwards** – Programme Manager, North

**Liz Henderson** – Special Advisor, System Redesign

**Trisha Hatt** – Strategic Partnership Manager, Scotland

**Amanda Watson** – Project Manager, Electronic HNA

**Barry Keenan** – Project Manager, London

**Eric Davies** – Programme Manager, Midlands

**David Murray** – Health Economist, Evidence

**Monica Burchell** – Project Manager, Midlands

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**Workshop 5**
(focused on measurement framework)
30 November 2017, Birmingham

**Natalie Dale** – Senior Evidence Manager, Evaluation and Impact

**Claire Burley** – Senior Evidence Manager, Strategic Knowledge

**Colm Burns** – Evidence Officer, Northern Ireland

**Kelly Shiell-Davis** – Senior Evidence Officer, UK

**Anna Williams** – Evidence Officer, London

**Amanda Watson** – Project Manager, Electronic HNA

**Barry Keenan** – Project Manager, London

**Monica Burchell** – Project Manager, Midlands

**Sarah Allen** – Senior Evidence Officer, England

**Rebecca Wherrell** – Evidence Officer, Midlands

**Raluca Nagy** – Evidence Officer, South East and South West

**Caitilin McMillan** – Senior Evaluation Officer

**Marika Hills** – Strategic Partnership Manager, Wales

**Ginny Brink** – Partnership Quality Lead, Wales

**Julie Davies** – Senior Project Manager, Wales

**Dany Bell** – Specialist Advisor, Treatment and Recovery

**Ed Murphy** – Strategic Partnership Manager, South West

**Emer Sheehy** – Assistant Policy Analyst
Online reviews and input (people who were not in workshops 1 to 4)

Emily Bowman – Consequences of Treatment Project Manager
Sinead Clarke – UK GP Adviser Lead for Treatment and Recovery
Libby Potter – Senior Learning and Development Manager, South West & Midlands
Kim Bowles – Partnership Manager, South West
Wendi Abraham – Partnership Manager, South West
Lyn Bruce – Learning and Development Manager, South West
Sinead Parry – Partnership Quality Lead, South West
Sue Littler – Partnership Quality Lead, South West
Dr Nicola Harker – Macmillan GP Advisor, South West (on Measurement Framework)
Ed Murphy – Strategic Partnership Manager, South West
Sophia Nicola – Primary Care Advisor
Anthony Cunliffe – UK GP Adviser Lead for Prevention and Diagnosis
Peter Nightingale – UK GP Adviser Lead for End of Life
Lynn Green – Programme Manager, South East
Tania Anastasiadis – Associate GP Advisor, London (on the Definitions Document)
Tatyana Guveli – Project Manager, London (on the Outcomes Framework)
Azmina Verjee – Recovery Package Project Manager at the Homerton Trust, London
Appendix 2

Learning, reflecting and refining the Definitions Document and the Outcomes Framework – Piloting to start in 2018

It is likely 2 or 3 cycles will be necessary for ‘End’ definitions and outcomes.

‘End’
Most apt ‘core’ and outcomes contexts

‘Good Enough’ Definitions Document and Outcomes Framework

Measurement Framework
Identify the right questions to ask and the relevant data to collect

Refine and develop Definitions Document and Outcomes Framework

Piloting Data collection
Multiple methods – quant and qual

Data analysis
What has been delivered, what changes are happening

Synthesis
Develop key findings and use to adapt and improve

Critical reflection
Use data to discuss and critically reflect with key stakeholders

The Recovery Package
Definition of the core

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You may have cancer, but you are still you. Macmillan is here to help you live life no matter what. We’ll give you the support you need to hold on to who you are and what’s important to you.

From the moment you’re diagnosed, for as long as you need us, you can lean on Macmillan. Call us free on 0808 808 00 00 or visit macmillan.org.uk

Life with cancer is still life – we’ll help you live it.