Long Term Recovery and Improved Outcomes supported by delivery of an effective Recovery Package

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National Learning
Economic case

- HNA/EHNA/TS/CCR low cost to implement
- HWBE can have higher cost depending on setup costs
- A benefit and a challenge is flexible delivery in a local context
- Lack of comparable data
- Demonstrate value for money despite lack of quantitative data due to low cost delivery
Challenges and Barriers to delivery

• Information Technology
• Capacity
• Workforce
• What is the right time and place to deliver each intervention to achieve greatest impact?
• Cultural shift required for new ways of working
• Training – to achieve some standardisation in the quality of each intervention
• Demonstrating impact
Outcomes

For the individual

• better able to self-manage, improved self-efficacy, knowledge and confidence

• Improves accessing and re-accessing the system; making connections and developing supportive relationships

For the system

• decreased use of unplanned appointments, more efficient use of resources, and new opportunities for care and support.

• Improved workforce skills and competence in cancer support and care

• Coordination and communication across settings
Links and Interdependencies

- Stratified Pathways
- Management of own health
- Workforce
- Learning & development
- Role of Primary Care and community
- Self monitoring
- Social prescribing
- Diversity
- Across Time of Need
- Lifestyle
- Quality of Life
- Health literacy and activation

People have other LTC

Supporting self-management

Assessment and care planning

Information, financial, and work support

Managing consequences of treatment

Physical activity and healthy lifestyle

Treatment summary and cancer care review

Health and wellbeing event

Recovery package

Managing consequences of treatment

Supporting self-management

Supporting self-management

Supporting self-management
Different models of delivery

Services with elements of RP across the UK

- **Glasgow**
  Social prescribing service meeting non-clinical needs

- **Merseyside & W Cheshire**
  Social prescribing service meeting non-clinical needs

- **Gloucestershire**
  Rehabilitation service

- **Berkshire**
  Rehabilitation service

- **Dundee**
  Social prescribing service meeting non-clinical needs

- **Durham**
  Social prescribing service meeting non-clinical needs

- **Doncaster**
  Information and financial support service linked to community providers

- **Bromley by Bow**
  Social prescribing service meeting non-clinical needs

The services highlighted are the ones that the Social Investment Team have and/or are currently supporting.
Partnership programmes across the UK
Experience of Holistic Care and the Recovery Package
The mix of patient needs is constantly evolving throughout the cancer journey.

“People change so much as they come to understand their journey – what they need from me changes along with that”
Chemotherapy Nurse, Birmingham

“That first time you hear the words cancer… you just want to know what’s going on you can’t think ahead to what it means for you”
Susan, Cardiff

HCP interactions, perspectives and assessments lose relevance as patients move through diagnosis, treatment and beyond.
A snapshot approach to assessment provides limited value for both patients and healthcare professionals.

Assessment carried out at diagnosis suffers from multiple barriers: Patients are focused on their diagnosis and are thinking more clinically and short-term, than holistically and long term, and they lack strong HCP relationships which could facilitate the process.

During treatment, patient needs can change on a week by week basis as a result of the treatment itself, side effects and other factors that become more relevant the deeper into their journey they go e.g. support of work and friends and family.

Beyond treatment, there is an on-going need to understand patient needs, but a single assessment taking place here is too late in the journey to meet needs as they emerge – leaving support as reactive, rather than allowing it to be proactive.

“I sometimes see the eHNAs for patients that were done right at the start – but they didn’t know what impact their treatment was going to have on them and didn’t know what they’d need.”

Chemotherapy Nurse, Birmingham

A continuous approach to assessment has the potential to better account for the dynamic nature of patient’s needs profiles.
Where some are keen to be real partners in the treatment of their cancer – others actively avoid involvement

Different strategies are required for patients at each end of the spectrum – as well as an ability to differentiate between them

**Passive Receivers**

Driven by fear, a sense of denial, or acceptance, there can be a desire to shy away from their own experience as they struggle with their own reality.

They require clear guidance and sign-posting to access support

“He doesn’t want to know – he doesn’t ask any questions, just does what he’s told”
Anne, Duncan’s Wife, Glasgow

**Active Partners**

Taking a strong interest in all aspects of their cancer can act as a counter balance to the loss of control that a diagnosis brings.

They need to be fully informed and brought along the journey as part of the team

“My biggest unmet needs was not being used as a resource more”
Ian, Ipswich

Colour tabs relate to the relevant segments from the 2.5million segmentation
Patients’ biggest challenges often relate to adjusting to their new normal – both during and after treatment.

Beyond their clinical recovery, adjusting to their new lives, limitations, expectations, realities etc. can require coming to terms with a new version of themselves and of what their life is going to look like – even if the actual change is relatively minor, the perception of change can have a significant impact in its own right.

“you have to accept that things aren’t the same, which for someone like me is really hard – I want to get back to where I was, better than where I was. But that’s not easy and takes all kinds of support”

Tricia, Liverpool

This can require as much work as clinical aspects and holistic care has the potential to facilitate this – though often remains undervalued as a solution.
Holistic care suffers from a lack of ownership with few clearly demarcated responsibilities or points of contact.

Patients are surrounded by a range of healthcare professionals who interact with them as relevant – they have clear understanding of their clinical roles and responsibilities and generally know both what questions they should direct to them and also how. For holistic care, this is almost entirely absent.

This is directly contrasted with clinical care where roles and responsibilities are clear – alongside relevant channels of communication.
Lack of ownership is exacerbated by structural barriers faced by HCPs – limiting the definition of ‘holistic’ they can support

“We’re taking on ‘x’ new patients a week. We’re stretched to our limits and are already doing everything to look after our patient’s physical and mental wellbeing but there is only so far we can take this”

Oncologist Nurse, London

As a result the default is for HCPs to prioritise their element of a patient’s clinical care without ever achieving a clear picture of their overall holistic needs
At its worst, this creates a schism between patients and HCPs – with holistic care falling between the cracks

Patients:
• Disengaged with own needs
• Lack confidence in articulating them
• Feel holistic care is out of scope
• Don’t know where to turn

HCPs:
• Clinically focused on medical needs
• Time pressured and under resourced
• See as outside of their scope and expertise
• Unclear on ownership and own responsibilities

Both parties feel that they lack the tools and resources to help bridge this gap and create better holistic welfare experiences
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<td>HCP UNDERSTANDING OF ‘HOLISTIC’ COVERS LESS GROUND THAN PATIENT EXPECTATIONS</td>
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The Patient Experience of the Recovery Package
“I mean I might have – there was a talk I went to about eating healthily and that sort of thing but I don’t think that was to do with my cancer, it was just something one of the girls mentioned”

Irene, Glasgow

“I’ve never heard of a ‘Recovery Package’... I think I did a questionnaire at some point but I don’t remember what it was for”

Tricia, Liverpool

“I’ve got a big folder with all my paperwork in so I suppose I do have that – but I’m not sure how it fits with anything else?”

Steve, Coventry

“That sums it up doesn’t it – you’re telling me about something that we’re supposed to have benefited from and we’ve never even heard of it”

Sylvia, Birmingham
Overview

Initial Findings

1. Understanding of recovery package:
EHNA/HNA is the most well understood component, but other components appear to be a source of confusion for multiple stakeholders.

2. Perceived varying impact of components:
EHNA/HNA is the perceived as having the greatest ‘impact’ for PABC, but this varies for the other components.

3. Variation in when EHNA/ HNA is delivered during the cancer journey:
Considerable variation across most sites, both in terms of when and frequency of EHNA/ HNA.

4. Lack of linkage between components:
Components are frequently described and implemented by partners as ‘individual interventions’, instead of being interlinked components.

5. Variation & user journey:
Not necessarily a negative or positive, but it is unclear as to what is driving this and if ‘patient needs and preferences’ are a factor.

6. Potential barriers to engagement:
Broad support for the recovery package from multiple stakeholders, but ‘lack of business tools’ and ‘clear definitions’ acting as barriers to implementation.
Three broad cancer groups

**Group 1**
Many live for more than a decade

**Group 2**
Most similar to a long-term condition

**Group 3**
Survival for the majority is short term

Relative five-year survival

- Prostate – stage 1 to 3
- Testicular
- Uterus – stage 1
- Cervix – stage 1
- Kidney – stage 1
- Melanoma of skin
- Breast – stage 1 to 3
- Colorectal – stage 1 and 2
- Hodgkin lymphoma
- Non-Hodgkin lymphoma
- Colorectal – stage 3
- Bladder
- Myeloma
- Ovary
- Cervix – stage 2 to 4
- Uterus – stage 2 to 4
- Kidney – stage 2 to 4
- Metastatic prostate
- Metastatic breast
- Stomach
- Brain
- Oesophagus
- Lung
- Liver
- Metastatic colorectal
- Mesothelioma
- Pancreas

The Person at the Centre to achieve benefit and outcomes
Title: Unclear Proposition

Problem Statement:
The elements in the Recovery Package are intended to reveal the personalised and holistic care plan needed for people living with cancer which could positively impact their wellbeing. However, the elements are not clearly understood and are varied in implementation, primarily due to the lack of a shared understanding. This makes it difficult for a person living with cancer including the health and social care professional to understand the benefit of such tools and interventions, consequently missing out on opportunities for support due to a lack of engagement with it.
Title: Unclear Core & Breadth

Problem Statement:
Delivery partners do not have clear understanding on how to identify the core of the Recovery Package within their local area and unique to a person living with cancer, and the breadth of services that may exist outside of the core that people may benefit from being signposted to.
Title: Cancer & Me

Problem Statement: Due to the impact of cancer on a person’s identity and the new and evolving nature of their needs, a static snapshot assessment is not the most helpful approach in identifying the evolution of their needs.
Title: Unmet Preferences

Problem Statement:
People living with cancer’s preferences are not always being fully acknowledged or addressed. Subsequently patients may not be able to play the role in their care that would prefer to. When imposing decisions are made or assumed, it is more difficult for the person living with cancer to engage in their cancer care and accept expertise and help.
Title: Lack of Infrastructure

Problem Statement:
Due to a lack of structure in supporting the delivery and ongoing management of the Recovery Package and the visibility into services a person living with cancer has been recommended or used, the cost of this is that the value in proper signposting and connections is not being demonstrated. This is not only within a clinical landscape of care delivery, but also between community based support services.
Sustainability
Implications

1. Recovery Package elements need to be continuously available and not used as a single snapshot

2. Recovery Package elements need to work hard to reach the end user and not presume they will be found

3. Recovery Package elements need to tell a clear story as to how they can help experience – beyond the short-term

4. Clear lines of responsibility for different element of the Recovery Package – well sign-posted to PLWC

5. The Recovery Package needs to be presented in a coherent way to provide a fully immersive experience

6. HCPs to be primed to look wider than holistic healthcare, and into holistic welfare – and PLWC given permission to expect this
Practical Support
Having a vision for what good looks like

- A collaborative culture in which empowered and informed patients take more active roles in their recovery short and long term
- A cross community structure of collaboration between acute, primary, community, commissioners and 3rd sector organisations; as well as PLWC
- Sustainable, evidence based, cost effective pathways supporting long term recovery and health and well being
- Seamless care between specialist and generalist providers
- Transparent evaluation and reporting with standardised measures of outcome and patient experience
## Challenges faced by some

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Resources:

These can be ordered from:
be.macmillan.org.uk/recoverypackage

e-learning resources - learnzone.org.uk/recoverypackage