



CANCER CARE
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South Yorkshire, Bassetlaw and North Derbyshire Cancer Alliance Board

Title Living with and Beyond Cancer programme - update for boards August 2017	Sponsor Lesley Smith, Chair of the South Yorkshire, Bassetlaw and North Derbyshire Cancer Alliance, Chair of the LWABC Programme Board and Accountable officer Barnsley CCG
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Purpose The purpose of this paper is to highlight progress of the Living with and beyond Cancer programme to date, which can be shared with Cancer Alliance member organisation boards.	
Recommendation The Board is asked to NOTE the progress of the programme and members are asked to SUPPORT by sharing this update with their own organisations board.	

1. Background

In November 2015 agreement was reached with Macmillan and the Commissioners Working Together programme to work in a programme approach to implement Living with and beyond cancer (LWABC) over five years, across the eight CWT localities. Along with Macmillan's experience in this field and our joint experience of working together regionally, Macmillan committed up to £6.4m during the life of the programme to support the transformation required to implement the programme.

The programme aim is to enable every adult living with breast, colorectal or prostate cancer in each of the eight localities to have access to the LWABC model of care from diagnosis onwards by 2020.

The programme was launched in April 2016, at the same time we saw NHSE launch the first guidance "Commissioning person centred care for people affected by cancer".

The guidance is based on:



- The Cancer Taskforce strategy (2015) recommending the implementation of:
 - A. **Stratified pathways of care** for Breast, Colorectal & Prostate cancer
 - B. **The Recovery package** a set of essential interventions designed to deliver a person centred approach to care for people affected by cancer.
- Whole person, whole pathway approach
- Long term condition management of Cancer
- Commissioning for the individual rather than cancer in isolation
- Services need not be cancer specific
- Follow the principles of **PERSON CENTRED CARE**

In November 2016 the newly formed South Yorkshire, Bassetlaw & North Derbyshire Cancer Alliance agreed Living With and Beyond Cancer as one of the four priority work streams of the Cancer Alliance.

In December the 2017/18 and 2018/19 NHS planning guidance confirmed Living with and beyond cancer and specifically **Stratified pathways of care** and the **Recovery package** as a 'must do' in Cancer care.

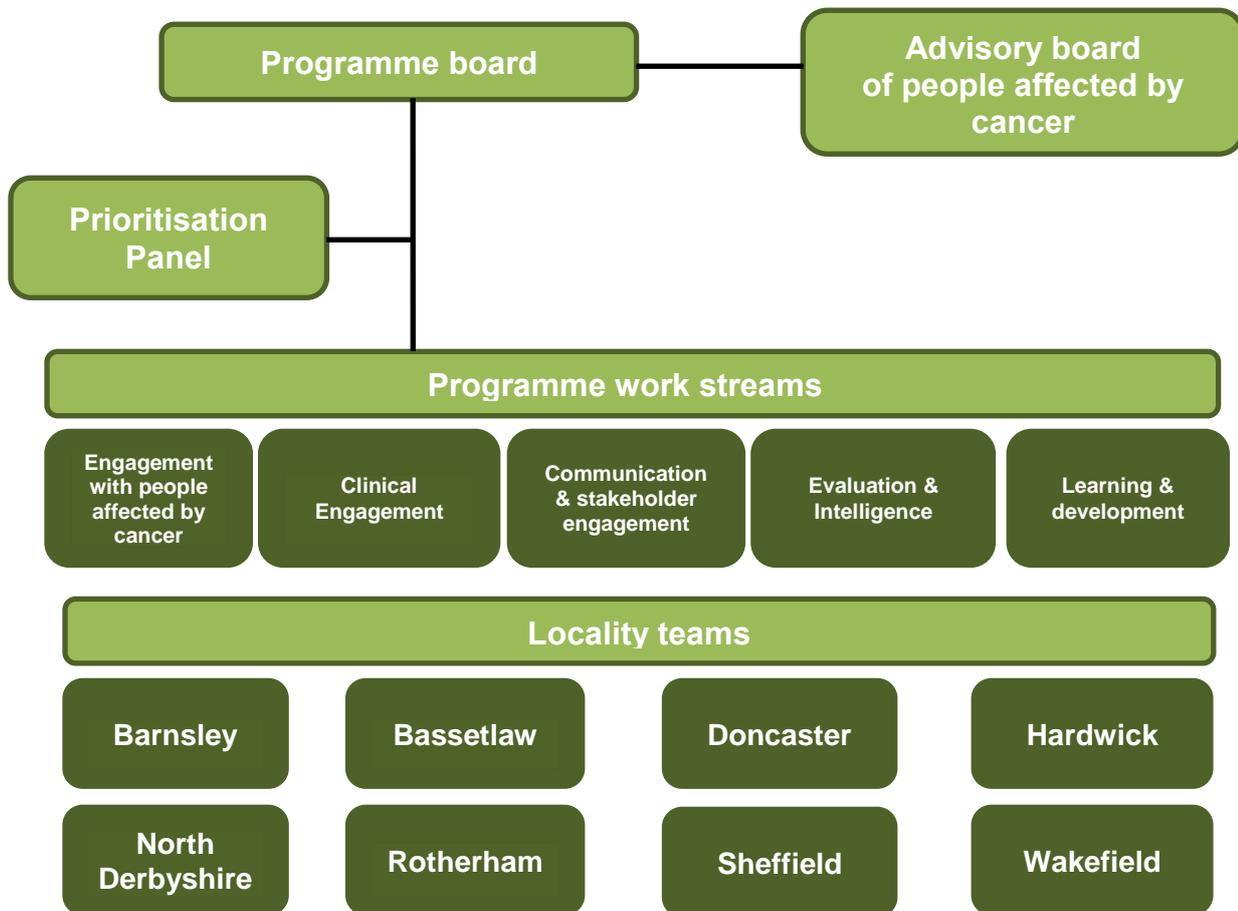
In January 2017 the programme was confirmed within the Cancer Alliance delivery plan and Cancer Alliance bid for transformation funding specifically to support the implementation of eHNA (as part of the **Recovery Package**).

This funding has now been agreed meaning the total additional funding for our region to implement Living With and Beyond Cancer is up to £6.8m.

2. Progress to Date

It is important to emphasise there has been excellent work already in our region to progress our understanding of cancer survivorship. The programme aims to adopt this learning along with what is happening nationally, at scale across our programme footprint. There are some great services already in place, with committed people working to deliver support for people affected by cancer.

Since the programme launch in April 2016 we have initiated the following **governance** structure.

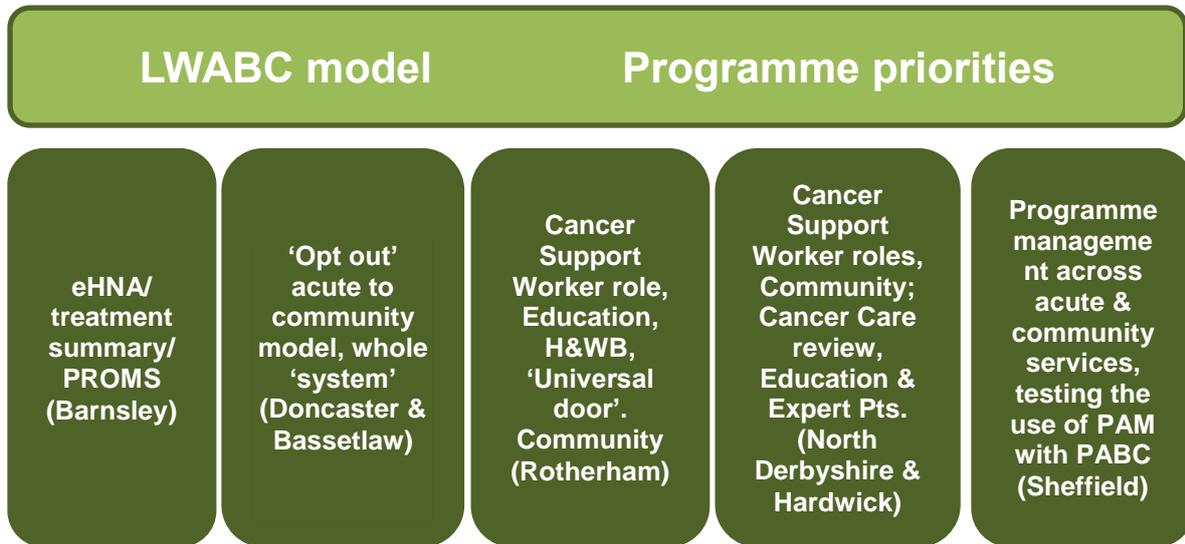


We are working through a **locality approach**, working as local place based systems with service providers, commissioners, community and voluntary sector and with people affected by cancer in locality teams.

To date we have approved additional funding in Bassetlaw and Rotherham with significant progress in each of the localities.

Whilst each locality is working on how to implement the LWABC model in their context at 'place', localities are also testing different approaches to the implementation (see below).

Essentially the approaches are either acute or community based or a combination of both. This learning is key to not only informing our learning across the programme as we progress implementation, but also learning in Macmillan and nationally as part of the NHSE national cancer transformation programme.



Our **Clinical Engagement** model is essential to enabling the **Risk Stratification**. We have been working at a tumour site level in three groups (Breast, Colorectal & Prostate) 'Clinical Delivery Groups'. To date this work has involved over 150 clinicians & managers from both providers and commissioners agreeing how to implement the new regional High value pathways, specifically around their follow up arrangements. These pathways stratify patients into cohorts based on clinical complexity and patients suitability for either earlier discharge, remote follow up or shared care.

As one of the four interventions in the **Recovery Package** we are testing the implementation of **e-Holistic Needs Assessment** across our acute trusts. There are two systems being tested across the programme; a Macmillan web based stand-alone system and a system which is integrated into the trusts patient management system for cancer.

The Doncaster & Bassetlaw system are leading on testing the standalone system with Barnsley testing the integrated system approach. Both systems enable patients to either remotely complete their own assessment prior to attending clinic or on a tablet device in clinic; either whilst they are waiting for an appointment or with a member of the clinical team. Based on the information provided the system identifies the patient needs, enables the patient to score/rank their needs and generates a care plan based on those needs.

The **evaluation of the impact of the programme** is critical not only to enable us to effectively implement the programme, but also to support learning in Macmillan and nationally as part of the NHSE national Cancer transformation programme.

The way we have approached our evaluation with the Macmillan evidence team is by developing ‘**Theories of change**’. Theories of change go further than logic models to include key real life factors in systems including most fundamentally our ‘assumptions’ about how and why systems should work. Theory of change aims to:

- provide clarity about **what we think a programme will achieve and how** (emphasis on causality and explicit assumptions)
- enables **stronger programme design, monitoring and evaluation**.
- should be **revised over time** as programmes evolve and evidence becomes available
- is ideally developed at **design stage** but adds value at any stage of the programme cycle



Following a procurement process we have appointed the Tavistock institute to work with us over the life of the programme to facilitate and support the evaluation of the programme considering our four theories of change:

- **Theory 1 - why work in a programme approach**
- **Theory 2 – how to bring about implementation of LWABC model**
- **Theory 3 – the LWABC model itself and changes it brings about**
- **Theory 4 – how the benefits will be sustained over time**

Fundamentally this process has enabled us to ‘unpack’ **the Recovery Package**, to ask the “so what?” question; by implementing the Recovery package what is the impact for people affected by cancer and those who are working to support them, the “so what?” question.

For example when we consider **Holistic Needs Assessment** as just one element of the **Recovery Package**. We know that one of our huge challenges is how we link people affected by cancer to the support in their local community. Therefore being able to identify those people with additional needs utilising a standardised assessment process sounds like a good idea however

- There is a real risk of HNA being a ‘tick box’ exercise, where we introduce a process with a target such as “70% of people have a HNA by day 31 & day 62”, with no understanding of the benefit for people affected by cancer.

- At this stage there we have heard lots of ‘Person centred’ language and rhetoric, with limited evidence of implementation.
- The system has previous experience of promoting person centred planning for example for people with Learning Disabilities over the past 30 years. From this wealth of experience we know that the plan is simply the first step, therefore avoiding seeing the HNA as a process measure is critical. The HNA is simply a tool on which to capture a conversation.
- Therefore by ‘unpacking’ **the Recovery Package** we know we need to focus on ‘Having ‘**Conversations**’ **person centred conversations with a meaningful shared care plan** ... and the elements of the Recovery Package (eg: HNA, Treatment summary, Cancer Care review) are simply tools or enablers.
- Through testing the locality approaches we are trying to understand **Who should initiate the conversation? When and Where?** should conversations happen. For example we know from audits of existing HNA conversations in patients with multiple needs identified:
 - if conversations happen in a **hospital** – the uptake of support services can be as low as 0%.
 - however if conversations happen in a **community setting**, the uptake of support services can be as high as 92%.

Engagement with People affected by cancer is key ensuring the changes we make are grounded in the real experiences of people affected by cancer. So far the programme is:

- Utilising existing intelligence in **localities** and by building on what we already know from the national, regional and local engagement work
- We have **Principles for engagement** with people affected by cancer – which we consulted with the public during summer of 2016
- **Building on co-production** experience and skills across the footprint with up to 60 people affected by cancer per locality involved in co-designing solutions.
- Testing specific **work via the voluntary and community sector** organisations to engage reach/seldom heard groups.
- Using intelligence from conversations with people affected by cancer **to inform a decision making framework** at the Prioritisation panel.
- Established an **Advisory board of people affected by cancer** – with 11 people affected by Cancer representing all the localities. This Advisory board is helping us make decisions about how the programme is working.

A high level summary of progress by programme projects and locality teams can be found in **Appendix 1**.

3. Timetable

A snap shot of the high level Milestones from the programme plan can be found in **Appendix 2**.

Our priority next steps for the remainder of 2017 include:

- Progressing the agreement and modelling of follow up care through the three tumour site clinical delivery groups.
- Begin testing both approaches to the use of eHNA.
- Working with Bassetlaw & Rotherham on evaluation work to understand the impact of the early changes being made.
- Embed the Advisory board's role into our decision making process.
- Supporting localities to agree their plans with initial investment.
- Development of medium and long term learning and development offer to support changes being made across localities.

4. Recommendations

The Board is asked to **NOTE** the progress of the programme and **SUPPORT** by sharing this update with their own organisations board or governing body.

Appendix 1



Project/Scheme Name	Ref	Project Lead	Planned Completion Date	Progress (RAG)	Comments <i>(Include reasons for Amber and Red assessments)</i>
Clinical Engagement model		Hayley Williams	Ongoing	G	Lead CNS now meeting regularly. Clinical delivery groups - next meetings in August. CDGs well attended/ agreed HVP/ meet again to refine and agree risk stratification and follow up.
e-HNA/treatment summary		Hayley Williams	Ongoing	A	Funding agreed, initial meetings with partners including Barnsley as first test site to use Infoflex in May. Further testing using the Macmillan web based eHNA across Doncaster & Bassetlaw, with interest from Chesterfield & Rotherham.
Programme Evaluation		Richard Metcalfe/Sarah Allen	Ongoing	G	Tavistock Institute appointed, initial implementation meeting held, planning to start conversations with Bassetlaw & Rotherham.
Communications		Laura Boyd	Ongoing	G	Ongoing work plan, looking to develop 'meaningful conversations' film by December.
Engagement with PABC		Richard Metcalfe/ Ian Margerison	Ongoing	G	First Advisory board 26 th July 2017.
Barnsley		Richard Metcalfe	Ongoing	G	PDD submitted following locality group support for panel conversation in August.
Bassetlaw		Richard Metcalfe	Ongoing	G	Implementation phase this quarter and evaluation conversations are starting. Exploring use of stand alone eHNA across the Doncaster & Bassetlaw system.
Doncaster		Richard Metcalfe	Ongoing	A	Locality group working toward PDD in September. Exploring use of stand alone eHNA across the Doncaster & Bassetlaw system.
Hardwick & North Derbyshire		Richard Metcalfe	Ongoing	A	Follow up conversations post PDD panel approval, return to panel following locality conversations
Rotherham		Richard Metcalfe	Ongoing	G	PDD 2 phase approach signed off at May Panel, now entering implementation phase.



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Sheffield		Richard Metcalfe	Ongoing	A	PDD in early draft support by STHFT. Potential for initial panel conversation in September.
Wakefield		Richard Metcalfe	Ongoing	G	PDD underdevelopment.

Milestones	Status	Date	Phase 3 Programme												
			2015/16		2016/17		2017/18		2018/19		2019/20		2020/21		
			Q1/2	Q3/4	Q1/2	Q3/4	Q1/2	Q3/4	Q1/2	Q3/4	Q1/2	Q3/4	Q1/2	Q3/4	
Engagement on LWABC programme approach	Complete	Jan-16													
Macmillan internal funding bid submission	Complete	Aug-15													
Phase 3 Programme initiation document completed	Complete	Sep-15													
Macmillan funding approval	Complete	Sep-15													
Macmillan funding approval years 4 & 5		Mar-19													
LWABC programme agreed by Working Together	Complete	Nov-15													
LWABC launched	Complete	Apr-16													
Programme Board and governance structure operating	Complete	Mar-16													
Local Implementation teams in place	Complete	Sep-16													
Local implementation plans developed		Sep-17													
Locality & programme testing															
Proposals around Risk stratification															
Case for change/business case development															
Pre consultation/Consultation															
Pre-implementation work & transition															
Commissioning - Final specification															
Full implementation															