

# **Commissioning Living with and Beyond Cancer in Yorkshire and Humber; an Overview.**



# **Document Title – An Overview of Commissioning Living with and Beyond Cancer in Yorkshire and Humber**

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## 1 Summary

There are an increasing number of people living beyond a diagnosis of cancer, and this number is set to rise. A fundamental shift is required in the way in which we support cancer survivors to lead a healthy and active life – this is a national strategic priority and included in Achieving world-class cancer outcomes: a strategy for England 2015-2020<sup>1</sup>.

A measure of good practice is the extent to which cancer patients have access to a Recovery Package.

The national Living with and Beyond Cancer Programme, undertook a national survey of Clinical Commissioning Groups (CCGs) in 2014, however the results from Yorkshire and Humber were variable. To understand the local position in more detail the Strategic Clinical Network (SCN) repeated the survey in October 2015.

This report provides information on

- The outcome the Yorkshire and Humber CCG survey
- Recommendations for next steps resulting from this work
- Current national developments
- Proposed next steps to progress the work of making improvements for people Living with and Beyond Cancer.

## 2 The Role of the SCN

The Cancer SCN works with the organisations that provide and commission cancer services to improve existing services and to develop new approaches for;

- Increasing awareness and diagnosing cancer early
- Treating and caring for people who have cancer
- Helping people to recover from or live with cancer

We focus on the patient's journey - which can be complex, so that this is well coordinated.

We will have succeeded if

- We are valued as a catalyst for improvement by organisations across Yorkshire and Humber
- We are effective in helping organisations make decisions that are focused on the needs of patients and based on sound clinical evidence
- We can demonstrate a significant contribution to improving the outcome and experience of care for patients.

**This report is aimed at encouraging improvement by identifying what can be done to support commissioning of the Recovery Package.**

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<sup>1</sup> <http://www.cancerresearchuk.org/about-us/cancer-taskforce>

### 3 Background; the national Living with and Beyond Cancer Programme

There are currently 1.8 million people in England living with and beyond a diagnosis of cancer, and this number is set to rise by 3% each year. Cancer survival rates are at an all-time high. There is an increasing demand for services and a high level of unmet need. A fundamental shift is required in the way in which we support cancer survivors to lead a healthy and active life – this is a national strategic priority.

To take this forward the national Living with and Beyond Cancer Programme was established; a partnership between NHS England and Macmillan, aimed at embedding the findings of the National Cancer Survivorship Initiative (NCSI) into mainstream commissioning (more information go to <http://www.ncsi.org.uk/favicon.ico> )

One of the key recommendations is that all cancer patients have access to a '**Recovery Package**' which includes

- a holistic needs assessment
- a treatment summary
- a cancer care review
- a patient education and support event

### 4 The National Baseline Survey

In autumn 2014, NHS England commissioned the Living with and Beyond Cancer; Baseline Report, which aimed to describe the extent to which CCGs were commissioning the four elements of the Recovery Package.

The Yorkshire and Humber SCN supported this review, however, completion of the national survey by CCGs across Yorkshire and Humber was variable. To gain a more comprehensive view of how the recovery package was being commissioned the SCN completed a second survey October 2015.

### 5 The Yorkshire and Humber CCG Survey

The survey was designed to build upon the results from the national survey, with additional questions to assess;

- The level of strategic collaboration
- Sharing of good practice
- Options for future work

The survey was emailed to all 24 CCGs across Yorkshire and Humber and followed up with emails and telephone calls, to increase the response rate; 17 out of 24 CCGs completed the survey, a response rate of 70% (for details of the methodology see appendix 10.1).

## 6 Survey results

The results of the survey are as follows;

### 6.1 Does your CCG have a cancer strategy that includes Living with and Beyond Cancer?

| Responses | Breakdown | Living with & Beyond Cancer Included |
|-----------|-----------|--------------------------------------|
| 17        | 10        | Yes                                  |
|           | 4         | In development                       |
|           | 3         | No                                   |

Over 75% of respondents had a cancer strategy that included Living with and Beyond Cancer.

### 6.2 Does Living with and Beyond Cancer feature as part of Long Term Conditions Plan?

| Responses | Breakdown | Part of the Long Term Conditions Plan |
|-----------|-----------|---------------------------------------|
| 17        | 6         | Yes                                   |
|           | 6         | In development                        |
|           | 5         | No                                    |

### 6.3 Do you commission the recovery package [in full] or elements of the recovery package?

| Responses | Breakdown | Prioritise or commission any other elements |
|-----------|-----------|---|
| 17        | 3         | Whole recovery package                      |
|           | 8         | Elements of the recovery package*           |
|           | 6         | No  |

\*colorectal, breast and prostate

### 6.4 Does your CCG prioritise or commission any other elements of Living with and Beyond Cancer such as Risk Stratified Follow Up or late/effects clinics?

| Responses | Breakdown | Prioritise or commission any other elements |
|-----------|-----------|---|
| 17        | 12        | Yes   |
|           | 5         | No  |

Further information on how the recovery pack was commissioned

- A shared care plan focusing on prostate and breast cancer.
- A pilot project with Macmillan and Age UK; to provide a ten week course focusing on health, welfare and emotional support.
- The CCG clinical lead is working with the Acute Trust on breast and bowel cancer survivorship.
- Late effects clinics and nurse led follow ups.
- Risk stratified follow ups for prostate, colorectal, breast, testicular and gynaecology.
- Living with and beyond cancer and survivorship identified as local priority areas for the future. The detail of this is currently being worked through.
- Risk stratified follow-up pathways: Three stratified pathways commissioned in breast, prostate and colorectal. The breast pathway is embedded and the prostate pathway is currently live. The CCG is now seeing increasing numbers of patients being discharged for GP follow up.

## **6.5 Do you work with a strategic group/body in your area?**

A number of CCGs responded to indicate that they are engaged in collaborative work with other organisations, ranging from Locality Groups, which typically include the local CCG and Hospital Trust (some of which focused specifically on Living With and Beyond Cancer) to the SCN which is Yorkshire and Humber wide.

## **6.6 What are the perceived barriers to implementing a commissioned recovery package?**

A number of responses were received to this question, which fall into three main areas;

### **1. Competing Priorities**

- Competing priorities within the health system; CCGs have a number of competing priorities only one of which was cancer.
- Competing priorities within cancer; progressing objectives relating to Living with and Beyond Cancer is not seen as important compared to delivery of treatment interventions and meeting the NHS Constitutional targets.

### **2. Lack of Capacity**

- Lack of capacity within commissioning to focus on this agenda; developing a service specification or commissioning recovery packages for each tumour site was seen as complex and time consuming.
- Lack of capacity within Primary Care to deliver the cancer care review for patients was also seen as an issue.

### **3. System constraints**

- Lack of clarity around tariff and funding streams.
- The level of internal change within acute trusts needed to deliver services differently against a background of increased demand (including the capacity needed for workforce development and training).

## **6.7 What are the enablers to implementing the commissioning of the Recovery Package?**

CCGs identified the following as helping progress work on this area;

### **Current enablers**

- Strategic support from NHS England and the Strategic Clinical Network.
- Having excellent relationships with provider colleagues.
- Having strong clinical leadership in both primary and secondary care.

## Future enablers

- Greater management capacity to focus on this issue.
- Further clarity regarding the practicalities of completing the Holistic Needs Assessment (when and by whom).
- Inclusion of cancer as a long term condition within the wider spectrum of healthcare.
- The recognition that implementation of risk stratified pathways would reduce follow ups and improve throughput, which would then help with Cancer Waiting Times achievement.
- Prioritisation through the National Cancer Strategy.

### **6.8 Is there any good practice that your CCG would like to tell us about when commissioning the recovery package or other initiatives for patients Living with and Beyond Cancer?**

A number of CCGs highlighted a number of programmes which included:

- Macmillan Survivorship Programme in Sheffield.
- Leeds Integrated Programme - including the patient educational programmes and support groups.
- Work with the voluntary sector on a grant scheme arrangement to commission survivorship services.
- Shared Care Programme on Prostate Cancer.

### **6.9 Would you be happy to share this information with the health community across Yorkshire and Humber?**

The majority of CCGs stated that they would be happy to share information with other stakeholders across Yorkshire and Humber.

### **6.10 Would you like to be part of a steering group that continues to do further development work on Living with and Beyond Cancer?**

A total of 15 out of 17 CCGs (88%) stated that they would like to contribute to further developmental work of Living with and Beyond Cancer across Yorkshire and Humber.

## 7 Conclusion

It is encouraging that most CCGs have a cancer strategy which incorporates Living with and Beyond Cancer and that most CCGs commission the Recovery Package (in part or as a whole), although it is clear from the findings that there are a number of challenges when commissioning services for people Living with and Beyond Cancer, including prioritisation, capacity and system constraints.

There are number of things that can be done at a local, Yorkshire and Humber and national level to overcome some of the barriers to change that have been identified.

- Including cancer in work on Long Term Conditions; some people who move beyond active treatment will require minimal long term follow up, while others will have complex health and social care needs. CCGs will increasingly need to consider how the needs of these patients are incorporated into the overall approach to long term conditions.
- Working collaboratively to maximise capacity; CCGs already identified the benefits of working collaboratively and there is the opportunity to work more effectively by pursuing joint work with other CCGs either across Yorkshire and Humber or at a locality level.

## National developments

**The Achieving World-Class Cancer Outcomes – A Strategy for England 2015-2020** was produced in July 2015 by the Cancer Taskforce. It identifies a number of recommendations relating to improving services for people Living with and Beyond Cancer (Appendix 9.2).

**The NHS Five Year Forward View** was published on 23 October 2014 and sets out a vision for the future of the NHS. Many of the proposals e.g. integrated primary and acute care systems and multispecialty community provider vanguards have a direct relevance to this issue as they address the need for more integrated care at a local level and promote models of integrated services across organisational boundaries. There are vanguard sites within Yorkshire and Humber and there is the opportunity to share learning from their experience.

The SCN will support the health system to progress work in this area as detailed below.

## 8 Action by the SCN to support commissioning of the Recovery Package and Risk Stratified Follow Up

- Encourage the local adoption of the national service specification for the Recovery Package (developed by the national Living with and Beyond Cancer Programme).
- Share the results of national work commissioned by the national Living with and Beyond Cancer Programme, aimed at making the economic case for implementation of the Recovery Package and overcoming issues with tariff (including financial/economic modelling).
- Developing a proposal to provide leadership via the Yorkshire and Humber GP Cancer Leads Forum, to assess implementation and the impact of the cancer care review in primary care.

- Encourage the development of strategies for incorporating Living with and Beyond Cancer as part of Long Term Conditions.
- Identify best practice for implementation of the Recovery Package and Risk Stratified Follow Up through the work on High Value Pathways (more information is available on the SCN website <http://www.yhscn.nhs.uk/cancer.php>)
- Spread and share innovation and best practice and encourage local adoption through networking; including the opportunity to use the experience of vanguard sites.

## 9 What are our next steps?

- This report will be circulated to all CCGs.
- The service specification developed by the National Living with and Beyond Cancer team will be circulated when available.
- The SCN will propose a project to the GP Leads Forum to focus on a specific piece of work on the Living with and Beyond Cancer programme.
- The SCN will communicate evidence of good practice through the SCN website and promote the prioritisation of Living with and Beyond Cancer by the three Strategy Groups within Yorkshire and Humber.
- The SCN will identify evidence based good practice for inclusion in the High Value Pathways for Colorectal and Prostate Cancer; to promote a consistent approach to the Recovery Package and Risk Stratified Follow Up.

# 10 Appendices

## 10.1 Survey Methodology

- **Survey Process**

A survey was designed based on the national baseline survey and sent to all 24 CCGs in Yorkshire and Humber. The survey was completed by Commissioning Lead officers in CCGs and ran for a month. After 1 month, only 5 responses were received. The CCGs who had not responded were followed up by telephone and email prompt to complete the survey. 1 CCG colleague was unable to access the on line survey, therefore a Word document was emailed to them 2 CCGs also completed the online survey via telephone with support from the SCN. The total numbers of CCGs completing the survey then increased to 17.

- **Survey questions**

1. Does your CCG have a cancer strategy that includes Living With and Beyond Cancer?
2. Do patients LWBC feature as part of your Long Term Conditions Plan?
3. Does your CCG prioritise or commission any other elements of survivorship/LWBC such as Risk Stratified Follow-up or late/effects clinics?  
If yes please explain in more detail.
4. Does your CCG commission the whole or part of the Recovery Package?  
If yes please explain in more detail what part of the Recovery Package is commissioned?
5. Does your CCG work with a strategic group/body in your locality?  
If 'yes' Please provide more details about this strategic group.
6. What are the barriers to implementing commissioning of the Recovery Package?
7. What are the enablers to implementing commissioning of the Recovery Package?
8. Is there any good practice that your CCG would like to tell us about when commissioning the recovery package or other initiatives for patients Living with and Beyond Cancer?
9. Would you be happy to share this information with the health community across Yorkshire and Humber?
10. Would you like to be part of a steering group which will look at further development work of LWBC across the Yorkshire and Humber region?  
Is there anything else you would like to add?

- **CCGs taking part**

CCGs that took part in the survey

- NHS Airedale, Wharfedale and Craven CCG
- NHS Bradford Districts CCG
- NHS Calderdale CCG
- NHS Doncaster CCG
- NHS East Riding of Yorkshire CCG
- NHS Greater Huddersfield CCG
- NHS Hardwick CCG
- NHS Harrogate and Rural District CCG
- NHS North Kirklees CCG
- NHS Leeds North CCG
- NHS Leeds South and East CCG
- NHS Leeds West CCG
- NHS North East Lincolnshire CCG
- NHS Scarborough and Ryedale CCG
- NHS Sheffield CCG
- NHS Vale of York CCG
- NHS Wakefield CCG

- **Lessons learnt from the survey; improvements to methodology**

- A pilot survey and testing of questions with a CCG would have been useful to test the survey.
- An explanation of the term strategic bodies to ensure uniformed understanding.
- To undertake further telephone surveys with CCGs that did not respond to increase the response rate.

## **10.2 The Achieving World-Class Cancer Outcomes – A Strategy for England 2015-2020**

### **Recommendations for Living with and Beyond Cancer**

REC 49 NHS England should pilot, through new or existing vanguard sites, assessment of holistic needs for cancer patients at the point of diagnosis, evaluating the benefit of earlier palliative care and/or intervention from Allied Health Professionals (AHPs).

REC 63 The NHS and partners should drive forward a programme of work to ensure that people living with and beyond cancer are fully supported and their needs are met. This should include approaches to reducing and managing long-term consequences of treatment. This could include understanding how tested approaches such as trigger questions can be embedded into clinical practice, as well as approaches to ensuring that specialist services for complex problems arising from cancer treatment are commissioned

REC 65 NHS England should accelerate the commissioning of services for patients living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the Recovery Package by 2020. In addition, NHS England should work with NICE to develop a guideline, by mid-2016, for a minimum service specification, building on the Recovery Package, thereafter to be commissioned locally for all patients, together with a suite of metrics to monitor performance. This specification would be expected to evolve over time, as resources permit. Initially this specification could include the following elements:

- A holistic needs assessment and a written individualised care and support plan at key points across the pathway. The patient should agree with and own this plan which should be shared with their GP or other designated local healthcare professional. It should take in to account social circumstances, mental health needs, and any co- morbidities.
- Information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years.
- Potential markers of recurrence/ secondary cancers and information on what to do in these circumstances.
- Key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent.
- A cancer care review to discuss ongoing needs and completed by the patient's GP or practice nurse.
- A treatment summary completed at the end of every phase of acute treatment, sent to the patient and their GP.

- Access to a patient education and support event, such as a Health and Wellbeing Clinic, to prepare the person for the transition to supported self- management, including advice on healthy lifestyle and physical activity.
- Signposting to rehabilitation, work and financial support services.

REC 73 CCGs and Health and Well Being Boards (HWBs) should work to identify and promote best practice in approaches to support people living with and beyond cancer. They should involve individuals and organisations beyond the NHS, for example employers, community organisations, and charities.

REC 74 NHS England should work with partners to ensure that supporting people with cancer to return to work is a key focus. This should include ensuring that return to work is fully integrated into assessment and care planning and should encourage the commissioning of vocational rehabilitation services.

### **10.3 Glossary of terms**

|      |   |   |
|------|---|---|
| CCGs | – | Clinical Commissioning Groups           |
| HWBs | – | Health and Wellbeing Board              |
| LICS | – | Leeds Integrated Cancer Services        |
| LWBC | – | Living with and Beyond Cancer           |
| LTC  | – | Long Term Conditions                    |
| NCSI | - | National Cancer Survivorship Initiative |
| SCN  | – | Strategic Clinical Network              |