

**Living with and beyond
Cancer Pathway Board
Annual Report 2014/15**

Pathway Clinical Director: Wendy Makin
Pathway Manager: Hodan Noor

Executive summary

This is the first annual report for the Living With and Beyond Cancer Board. This was established as a new pathway at the inception of Manchester Cancer in recognition of the importance of care and support throughout and after completion of cancer treatment, and the potential to enhance recovery and quality of life.

Headlines of key achievement this year;

- The **development of the board vision and strategy** to achieve the best possible health and well-being for cancer survivors.
- Undertook a **baseline mapping** survey with all of the **tumour site-specific** Manchester Cancer Pathway Boards, in order to build up a picture of which services are currently offered to patients as they approach the end of planned treatment.
- **Audit sampled the letters** generated by non-surgical oncologists closest to completion of treatment given with curative intent.
- **Joint education event** with the palliative care board to tumour site—specific boards to raise awareness of living with and beyond cancer and the palliative care interface with oncology care. The board also explored the views of people who **live alongside their cancer** and reported key themes to support needs.

'People, the government, the public, they put millions of pounds into cancer but do they really realise that cancer takes away your life, it takes away your health, it takes away your identity, it strips you of everything.' (LWC for over 10 years)

- Received **350K from Macmillan** to support and **accelerate the adoption of approaches** that address cancer survivorship.
- There is full **support and engagement of all Trust** representatives at pathway board.

Headlines of future work;

- Work will continue with **pathway directors and boards to improve the outcome and experience** to those living with and beyond cancer
- There is a specific target to ensure that **GPs and patients receive summary information** that the conclusion of planned treatment as this is an essential component of the Recovery Package.
- Identify best approach for those who **face living with cancer**, on-going treatment and a less certain future.
- We will also start work in another important aspect of cancer survivorship: **the impact of on-going and long term consequences from treatment**, in conjunction with all other Boards.

Introduction – the Pathway Board and its vision

This is the first annual report for the Living With and Beyond Cancer Board (LW&BC) .This was established as a new pathway at the inception of Manchester Cancer in recognition of the importance of care and support throughout and after completion of cancer treatment, and the potential to enhance recovery and quality of life.

This also reflects the growing numbers of people who live with a current or past ‘cancer experience’, currently increasing by 3% each year. 25% of these people live with long-term consequences of that cancer and its treatment.

In the UK the definition of cancer survivorship includes those who live alongside their malignancy, sometimes for a number of years, as well as those who are disease free and among the increasing numbers who are cured of their cancer.

The NHS Outcomes Framework 2014-15 makes clear that we have a responsibility to support people in recovery from significant illness and also when living with long term conditions, as well as improving survival rates.

Whilst better survival remains a priority for cancer, these other aspects increasingly apply as the numbers both of long term survivors’ increase and also those for whom cancer has become a chronic condition.

The Cancer Taskforce has signalled that the next cancer strategy for England 2015-2020 will place increased emphasis on better empowerment of patients in self-managing their condition; in rehabilitation and promotion of healthier lifestyles and promoting return to work. All of these can be influenced through the preparation and approaches that are adopted both through, and beyond, cancer treatment.

A core component will be the systematic use of the national ‘Recovery Package’ developed through the National Cancer Survivorship Initiative with Macmillan Cancer Support UK. In turn, this will also enable stratified pathways for follow up and surveillance.

The Living With and Beyond Cancer Board aims to collaborate with the other tumour-specific pathways to support patients (and those close to them) in this important aspect of care, and to enable GPs and other professionals outside of specialist cancer services to be better equipped to support them in secondary and community settings.

The Board works closely with the Palliative and End of Life Care Board and other groups including psychological support and AHP/rehabilitation.

The ‘Recovery Package’ includes the following, which should be in place towards or soon after the conclusion of planned cancer treatment: a holistic needs assessment and forward looking, an individual care plan; a comprehensive end of treatment summary shared with the patient as well as the GP; and a ‘health and well-being event’. These should be complemented by a cancer care review by the GP.

This annual report for the LWBC Board 2014-15

- Provides a summary of the work programme, outcomes and progress of the Board – alongside the minutes of its meetings, its action plan and its scorecard it is the key document for the Board.
- Provides an overview to the hospital trust CEOs and other interested parties about the current situation across Manchester Cancer in this particular aspect of cancer care.
- Meets the future requirements of the National Cancer Peer Review Programme (not yet defined in relation to cancer survivorship)
- Will be openly published on the external facing website

1.1. Vision

The following Vision was agreed and endorsed by the LWBC board members in 2015, including representatives of patients and carers and Macmillan Cancer Support:

The aim of the LW&BC board is for Manchester Cancer to achieve the best possible health and well-being for cancer survivors, whether for

- Those living with on-going cancer
- Those living beyond a diagnosis of cancer
- And for those close to them, who have also been affected by cancer

To raise the profile and awareness of cancer survivorship as part of modern cancer management and care

To work with, and support, Manchester Cancer site-specific Pathway Boards to provide excellent survivorship care.

To ensure that the views and experience of those who have been affected by cancer are listened to and inform all that we plan and undertake.

The Board developed its strategy in 2014 with a focus on the 8 key areas described below:

- To promote and enable consistent adoption of the tools for good survivorship care and to audit and monitor implementation of these against agreed targets for adoption into practice
- To map the use of different models of care across all settings and to share examples of good practice
- To review the capacity for survivorship support to meet needs across information, physical, psychological and social care domains and to highlight gaps and inform planning of future services
- To work with cancer-specific pathway boards, user representatives, Macmillan Cancer Support, primary care and community teams and the Strategic Clinical Network to develop approaches and protocols for

- effective recovery and rehabilitation
 - supported self- management
 - promotion of healthier lifestyles
 - monitoring and management of later consequences of treatment
- In conjunction with the Palliative and End of Life Care Pathway Board, to explore the needs of those living with cancer and to enable smooth transitions between different phases of the cancer journey
 - To develop and collate Manchester Cancer resources for survivorship accessible to patients, carers, professionals and the public
 - To identify where education and training is needed to develop knowledge, skills and confidence – for patients/carers and professionals
 - In collaboration with others, identify potential areas for research and opportunities to undertake this.

1.2. Membership

NAME	ROLE/ Trust
Wendy Makin	Director/consultant in palliative care and oncology, Christie
Kathy Pantelides	AHP/Rehab manager Christie
Ben Heyworth	Survivorship project manager Christie
Claire Higham	Consultant endocrinologist – Christie
Val Goode	Nurse clinician, Lymphoma team, Christie
Abbas Chittalia	Consultant clinical oncologist (breast and lung)- Christie and Stepping Hill
Claire Rehan	Clinical Psychologist, Bolton FT
Pat Jones	Lead cancer nurse, CMFT
Pauline West	Macmillan info and support manager, Trafford
Janet Parkinson	Macmillan info and support manager, East Cheshire
Karen Buckley	Lead cancer nurse manager, East Cheshire
Jo Keogh	Strategic cancer lead, PAT
Felicity Keeling	Macmillan info and support manager, PAT
Ian Ainscough	Macmillan info and support manager, SRFT
Julie Orford	Lead Macmillan Nurse, UHSM
Debbie Smith	Macmillan info and support manager, UHSM
Karen Livingstone	Physiotherapist breast/lymphedema UHSM
Julie Pieczarka	Macmillan info and support manager, Mid Cheshire
Vanessa Hickson	Keyworker, Tameside
Beverley Gail Meenan	Macmillan Lead Nurse for Cancer and Palliative Care, SFT
Julie Atkin-Ward	Macmillan Development Manager
Liane Harris	GP, Cancer Lead Bury CCG
Rachel Mcmillan	St Ann's Hospice and Neil Cliffe Centre representative
Ann-Marie Kelly	Patient Information Manager WWL
Sue Taylor	Patient representative
Brian Hixson	Patient representative

The Board benefits from broad representation including from primary care and commissioning as well as the acute hospital trusts; from cancer specialist professionals and those specialist in aspects of supportive care; and especially strong and effective user involvement.

The Board is particularly fortunate in having representation from Macmillan Cancer Support, given the charity's national role in cancer survivorship. A representative of the Strategic Clinical Network has also been in attendance.

The independent sector is represented by St Ann's Hospice which also serves as important cross link to the Palliative and End of Life care Board; the two Boards tasked a small joint working group in 2014 to consider the needs of those living with cancer.

Manchester Cancer has been working with Macmillan Cancer Support to develop its approach to the involvement of people affected by cancer in its work and have funded four user involvement manager (Band 6) post and a user involvement lead at 8a. The team are due to start during May and June of this year.

They will ensure that all pathway boards and groups have at least two people affected by cancer among their membership and that all people affected by cancer have the appropriate induction, support and training to play a full part.

The managers will also support their boards to undertake important work to improve patient experience, such as developing regional patient experience surveys, developing the use of patient-reported outcome measures and standardising patient information across the region.

1.3. Meetings

The board have met on six occasions during March 2014 and March 2015
Below is the list of dates including the link to Manchester Cancer website for a copy of all minutes.

25th of March 2014

<http://manchestercancer.org/wp-content/uploads/2014/09/LWBC-Board-Meeting-Minutes.pdf>

15th July 2014

<http://manchestercancer.org/wp-content/uploads/2014/09/LWBC-Pathway-Board-Meeting-Minutes.pdf>

15th September 2014

<http://manchestercancer.org/wp-content/uploads/2014/09/LWBC-Pathway-Board-Meeting-Minutes3.pdf>

21st November 2014

<http://manchestercancer.org/wp-content/uploads/2014/09/LWBC-Pathway-Board-Meeting-Minutes1.pdf>

20th January 2015

<http://manchestercancer.org/wp-content/uploads/2014/09/LWBC-Pathway-Board-Meeting-Minutes2.pdf>

25th of March 2015

<http://manchestercancer.org/wp-content/uploads/2014/09/Living-with-and-beyond-cancer-pathway-board-minutes-25th-March-FINAL.pdf>

2. Summary of delivery against 2014/15 plan

No	Objective	Alignment with Provider Board objectives	Tasks	By	Status*
1	Engagement with Manchester Cancer Pathway Boards and Beyond	Patient Experience	Develop the vision strategy of the Board	Apr 2014	
			Host an education event with the aim of engaging tumour pathway colleagues with the objectives of LWBC	Nov 2014	
			Invite pathway boards to have identify LW&BC champions	Nov- Mar2015	
2	Clinical services engagement in relation to survivorship	Patient Experience	Baseline mapping of survivorship initiatives, including elements of the Recovery Package across Boards and organisations	Nov- Mar2015	
			Undertake a baseline audit of information provision at conclusion of curative treatment for cancer by non-surgical oncologists	Nov-Mar2015	
3	Plan for effective utilisation of Macmillan Innovation Fund working with pathway boards	Innovation and Research	Identify key objectives to support the best use of the innovation fund	Nov- Mar 2015	
			Develop application process including criteria for selection and approval	Nov-Mar 2015	
			Produce a report of the achievements for the Innovation Fund and promote shared learning		Summer 2016
4	Develop patient/carer/relatives involvement strategy	Patient Experience	User involvement sub group of the Board has met and identified gaps to be addressed via Manchester Cancer User Involvement Strategy	Nov- Mar 2015	
5	To ensure that the aims of cancer survivorship as described in objectives 1 to 4 also meets the needs of those 'Living With Cancer'	Patient Experience	To identify the needs and concerns of people living with cancer, including those close to them and carers, who may also be affected	Nov- Jun 2015	
			To explore the extent to which the National Cancer Survivorship Initiative (NCSI) models meet these needs and identify any gaps or issues	Nov-Jun2015	
			To propose approaches that should be considered for people living with cancer in Greater Manchester and the extent to which current services are able to meet these	Nov-Jun2015	
			To identify and define interface between 'Living with/survivorship' and 'Palliative care/end of life care' and what is important to ensure smooth transition	Nov-Jun2015	
			To incorporate the needs of carers in all recommendations.	Nov-Jun2015	

*Green = achieved, Amber = partially achieved, Red = not achieved

3. Improving outcomes, with a focus on survival

3.1. Information

In contrast to the key outcomes of survival and length of survival which are so important for the tumour pathways, the focus of Living with and Beyond Cancer is upon the quality of life and experience for people following treatment for cancer. This is a relatively new consideration in cancer services so that there are as yet no specific national targets or service frameworks against which Manchester Cancer can currently benchmark.

Macmillan Cancer Support has estimated that there are currently 1.8 million cancer survivors in England of which 80,000 people are in Greater Manchester.

Outcomes in relation to cancer survivorship will depend upon the influence and collaboration with the LWBC Board in working with the other Tumour Pathway Boards, so that this agenda is evident in the patient pathways for all cancer sites in the future. It is anticipated that future national targets would include evidence of implementation of the Recovery Package.

In 2014-15 the new Board agreed that local outcomes in the first year would be based upon

- Engagement with tumour pathways in establishing their understanding of and commitment to cancer survivorship
- Undertaking some baseline mapping to identify the extent to which recovery package elements are being implemented and also current provision of end of treatment summary information

3.2 Baseline mapping

We undertook a baseline mapping survey with all of the tumour site-specific Manchester Cancer Pathway Boards, in order to build up a picture of which services are currently offered to patients as they approach the end of planned treatment.

The National Cancer Survivorship Initiative (NCSI) recommends that the following be undertaken:

- A review of the individual's current concerns/problems by the end of treatment (Holistic Needs Assessment, HNA)
- A comprehensive summary letter to be shared with the patient and their GP (End of Treatment Summary, or EoTS)
- Recovery and lifestyle advice, if possible via a health and wellbeing event/activity for appropriate patients.

The aim of these interventions is to improve recovery and confidence through the follow up period and beyond, while making sure those who need specific support can obtain this. Collectively, and in conjunction with a primary care-led Cancer Care Review, these interventions are known as The Recovery Package.

A survey asking about the levels of implementation of these interventions was initially sent to all Manchester Cancer Pathway Directors in September 2014. It also included a question about whether patients were routinely monitored for potential late effects/consequences of treatment. The responses were collated and presented to the LWBC Pathway Board at their November 2014 meeting.

3.2.1 Findings

Responses were received from individual Trusts regarding the specific tumour sites for which they provide services, rather than being co-ordinated at Pathway level.

31 responses were received in the first instance, including 8 from the Colorectal Pathway and 5 from each of Breast and Lung.

- 14 of the 31 respondents (45%) stated that some sort of HNA was completed with patients, although this was not necessarily the Macmillan HNA (Pepsi Cola, Somerset, and SPARC were all mentioned), and it was not necessarily carried out consistently.
- 10 respondents (32%) said that they prepared EoTS, usually in the form of a clinical letter to the patient's GP, which was copied to the patient in some cases.
- 11 respondents (35%) considered that they offered some form of Health and Wellbeing activity, but in the detailed responses it was apparent that these were open days, focus groups, support groups, and referrals to a Macmillan Support Centre, rather than what we would understand as a H&W event. It was positive to note that an additional 4 respondents offered a Macmillan HOPE (Help Overcoming Problems Effectively) course.

Due to the relatively low level of response from the Pathway Boards, the survey was repeated in February 2015, this time via the Lead Cancer Nurses at each of the Manchester Cancer Provider Trusts. This boosted the total number of responses to 46. The updated results were as follows:

- 28 out of 46 respondents (61%) stated that some sort of HNA was completed with patients
- 19 respondents (41%) said that they prepared EoTS
- 17 respondents (37%) considered that they offered some form of Health and Wellbeing activity, in addition to the 4 who offered a Macmillan HOPE course.

The updated survey demonstrated a substantive increase in Recovery Package activity across the Manchester Cancer region, and the proportion of patients being offered HNA is particularly encouraging.

3.2.2 Conclusion

The survey found that aspects of the Recovery Package are being implemented in some Pathways at some Trusts across the Manchester region, and there are some examples of excellent and innovative practice e.g. in the Colorectal Pathway. However, more needs to be done to ensure that all patients benefit from the implementation of the Recovery Package, and the LWBC Pathway Board will work with the other Pathway Boards to optimise this in 2015-16.

3.3 End of treatment summary information

This audit sampled the letters generated by non-surgical oncologists closest to completion of treatment given with curative intent. It is of course important that there is good information provision for those whose treatment is on-going (those patient who are 'living with' cancer) but these were not within the scope of this exercise.

The Christie Clinical Outcome Unit were asked to provide a list of hospital numbers for a sample of adult patients across solid tumour sites, in whom a decision to treat with curative intent had been made through MDTs approximately 12 months earlier.

Exclusions included those in whom treatment was not completed or became on-going because of progression or those who had primary surgery alone outside of The Christie. 102 patient pathways were sampled.

3.3.1 Findings

A letter was generated at the end of definitive treatment in 99/102 (98%) and in 83/102 (82%) this was within 6 weeks of completion of treatment. The majority of letters were written by the specialist oncology registrar or consultant; a few had been generated by a specialty doctor, nurse clinician, or a senior radiotherapy radiographer.

No examples were found of the Macmillan/NCSI template as the adopted model in use. Across the majority of teams, an unstructured end of treatment letter was produced with variable content. In general these usually included

- Cancer type and list of all treatment given
- Mention of acute side effects, often with advice on management
- Only rarely, a mention of possible late effects or need for monitoring
- Contact information implied from letter headers (but rarely was a specific person identified)
- The next outpatient appointment or transfer back to another consultant. Very few provided a clear outline for the follow up plan, including planned investigations over the next 5 years.

A few teams (lung, breast and gynaecology) are using a structured template letter. Where this had been adopted, there was certainly richer and more consistent information in the letters, including:

- Information given to patient, sometimes with a web link
- Actions for GP (although not regularly identified) such as tapering of steroids; on-going prescription of endocrine therapy, Vitamin D supplements; possible symptoms to be aware of or to note cardiotoxicity risk and current test results; to discontinue national screening (treated cervical cancer)
- More detail of specific contacts, such as the CNS numbers

Other notable findings:

While the majority of letters were written to the GP significant number were directed to an external consultant, with the GP copied in.

This might influence the content of the letter, possibly to the exclusion of 'obvious' information to another specialist, yet more of this might be extremely useful to other health care professionals.

Without exception the letter containing summary information came from the specialist team responsible for the *last component* of planned treatment. So if a patient had undergone several months of chemotherapy but went on to have radiotherapy, the last letter reflected the acute effects of the radiotherapy, rather than the potential impact of all treatment they had undergone.

Only a small number of letters appeared to be directly copied to the patient. Some letters did refer to information provided and discussed with the patient; some provided a link to specific information via the Christie website.

There were some examples of excellent template letters that had been developed for patients on completion of adjuvant chemotherapy for breast cancer, which complemented the GP letter and covered possible late effects and life style advice.

The head and neck team provided information about follow up after treatment to patients in a separate document. So while this audit focussed on the content of the letters generated at one time point, it does not mean that important information is not being provided to patients at other contacts.

There is however limited collation of such information in one document that relates to the entire patient pathway.

3.3.2 Conclusions

This was a baseline audit and sampled small numbers within each tumour group but it provided a picture of current practice.

While in 99% there had been some communication around completion of treatment, in many this was brief and did not cover the areas within the national EOTS recommended

model. There is relatively sparse inclusion of an on-going plan for monitoring apart from the immediate appointments; and very little on what the GP should be aware of, including later consequences from treatments; finally little mention of lifestyle advice given to the patient that the GP could reinforce.

Where structured letters were used there was inclusion of wider information and this was consistently covered for all patients.

Many patients undergo a sequence of different treatment modalities and there is a challenge in how to combine the important aspects of all aspects of complex treatment into a document that captures the entire pathway in such a way that provides a source of future reference, both for the patient and for the GP and other clinicians in the future.

When the GP is copied in to a letter rather than being the main recipient, this may reduce the likelihood of including general information or consideration the role of the GP in supporting the patient.

The findings from the audit were discussed at the LWBC Board and then presented at the Manchester Cancer Directors Forum in April 2015.

3.3.3 The following recommendations were proposed and agreed

- A structured, comprehensive end of treatment information summary information should be generated for all patients who undergo treatment with curative intent across all tumour sites.
- Patients should receive a copy of this, or alternatively a 'patient friendly' version that covers the same information
- Progress towards this will be re audited across all tumour sites:
 - By March 2016 all pathways confirm an agreed approach the format and content of the EOTS with reference to the Macmillan NCSI model template, customised if applicable for the disease site.
 - There should be agreement on how information relevant to all treatment modalities is captured.
 - All patients should be offered a copy of the summary document or alternatively, the same information presented in a format designed for the patient.
 - An audit of information provision will be undertaken in 2017 of those who completed treatment within the previous year:
 - Target set at 80% of eligible patient records will have evidence of a structured summary and evidence that this document (or in alternative format) is shared with the patient in 90% of cases.

4. Improving patient experience

4.1. Information

The patient representatives of the LW&BC Pathway Board have been involved in the user involvement subgroup and the Innovation Fund application process. They welcomed opportunity to comment on this report and have observed there appears to be a range of survivorship activities taking place, but there are concerns that they are not joined up.

“Patient involvement is vital particularly as most of the professionals are much younger and fitter than we are. They do not (yet) have cancer nor do they have to deal with the after effects of treatment.

There are vast quantities of good will and professional expertise but there can be an empathy gap that further could be addressed in matters of appropriate gender/sexuality, cultural and racial norms, particularly in the emotionally sensitive torso and pelvic areas, with the after effects and damage left behind following treatment.

It has been stimulating to have been involved with the Innovation [Fund] bids but surprising to find many things to have been considered as innovations which we assumed would already be parts of an essentially seamless service.

For the way forward we suggest a link-up with the Patient Manifesto currently being developed by the Christie Patient Reference Group.

In conclusion we continue to be more than happy to be part of a forward moving process where the voices of recipients of services are being taken seriously and used in the spirit of sometimes challenging but always constructive debate”.

4.2 Living With Cancer and Palliative Care sub group report

In 2014-15, a working group, drawn from both the LWBC and Palliative/EOLC Boards, was tasked to explore the views of people who live alongside their cancer and report back on the findings. They first reviewed work that had been undertaken by Cancer Research UK *Finding out the needs of people living long term with cancer [2012]* This had identified gaps in care, which were grouped into the themes below:

- Symptom management
- Support required to self- care/ sustain recovery and future models required for this
- Practical needs
- Social needs and financial concerns
- Emotional concerns/ uncertainty about the future
- Maintaining engagement with people LWBC

Focus groups were planned to discuss these themes and to try and extract any other important issues for patients living with cancer.

The focus groups were mixed groups of those living with cancer including some accessing palliative care services but did include others who are 'living beyond', as most groups have representatives from both. The patient representatives who were invited to participate included

- The Christie Patient Reference Group
- A focus group held at Wigan and Leigh Hospice
- A focus group held at Macmillan Trafford Centre
- A focus group held at Neil Cliffe Centre (part of St Ann's Hospice organisation)

In addition, a questionnaire was developed for completion on an individual basis or within a group setting, and circulated to Information Centre managers across Greater Manchester. The questionnaire was given to people visiting the Centres who were known to be living with cancer so was particularly useful in capturing the views of this group.

A total of 29 questionnaires were completed and 19/29 respondents were still receiving on-going treatments; 8 people were more than 2 years from their original diagnosis and 3 individuals had been a treatment pathway for more than 10 years. The full report is attached as an appendix but important findings are summarised below.

4.2.1 Findings

People LWC need more support with managing their symptoms and with their social, practical, emotional and financial needs than they have at present. The themes identified in the Cancer Research UK paper were an accurate reflection of gaps in care for this group, together with a need for a more 'joined up approach' to care by services and organisations.

When asked 'What it was like, right now, to be living with cancer?' the responses early in the pathway particularly reflected a need to get on with life, while coping with side effects and anxiety about the future was frequently mentioned. The transition period from treatment to follow up was mentioned by several as a difficult time when there was suddenly a loss of support.

As time goes by for someone living alongside cancer, there is a cumulative impact:

"I wake up with it I go to sleep with it, no matter how well I feel it's always at the back of my mind all day long. There's no cure for the cancer, they can hold it back but I have to live with that and it really affects my wife and the big question is who cares for the carer?" (LWC for over 8 years)

***'People, the government, the public, they put millions of pounds into cancer but do they really realise that cancer takes away your life, it takes away your health, it takes away your identity, it strips you of everything.'* (LWC for over 10 years)**

People were asked 'What were the 3 hardest aspects of living with cancer for them?' In the first 1-2 years there were again reflections on coping with anxiety, side effects and also the financial impact. As time went on, the answers reflected how tough it is to come to terms with a limited future:

'Cannot be cured, fear drugs will become ineffective, inability to think ahead'

'Having to tell people, telling my children, putting on a brave face for everyone & they do the same'

'Constant worry that every ache/pain is more cancer, people not understanding that although I look fit & healthy I am terminally ill, claiming disability & dealing with DWP'

The isolation felt by some respondents of being in this situation was evident, and several commented that they lived alone or had no close support.

People were asked about the burdens of being on treatment; again, earlier on, the impact of side effects was commonly mentioned but over time this changes to other aspects:

'Loss of job. Very hard to find a new job and now cannot tell employer/colleagues about cancer due to 'worry about loss of career/promotion opportunities'

'Basically having to take responsibility for my own self- management.

And I find it hard to be forward thinking and to keep going to my GP asking him to refer me on to different professionals.'

'I feel that I have to drive my cancer journey rather than being led.'

A question about the burden of being on treatment for the carer or family drew particularly moving responses and awareness of this clearly adds to the emotional cost of cancer for the individual and demonstrated how much life changed for everyone – yet

'My family didn't let me feel that I was burden.'

The powerful messages from people who face life with cancer challenge all of us to think hard about

- The extent to which we equip people to find their best way of coping with the long haul ahead
- To pay attention to the impact of on-going cancer, particularly financial and employment aspects
- To be mindful of isolation and the importance of access to both informal and professional support
- To help people with strategies to manage the psychological burden of living with cancer
- To provide better support for carers and families in all they do and to help the with their anxiety, distress and fear

4.2.2 Recommendations

These will be discussed further by the LWBC and palliative/EOLC Boards for inclusion in 2015-16 work plans

- **To review the use and adaptation of the Recovery Package to ensure it meets the needs of patients who are living with cancer:**
 - Develop models for Health and Well Being events specifically for patients Living With Cancer
 - To agree with tumour pathway Boards standard practice for provision of summary or update information at regular (at least 4-6 monthly) intervals for those on on-gong treatment pathways
 - To identify those who may be entering the last year of life to ensure timely Advanced Care Planning and provision for End of Life Care is anticipated in all settings
- **To influence a process for the above information (summary letters, HNA, ACP) should be shared with all involved professionals- between hospitals, with GP , community team and hospice.**
- **To explore non-clinical models for community-based support for those LWC and their carers:**
 - Wythenshawe Macmillan centre managed by Manchester City Council (Library service) has developed a model 'The Case for a Community Based Model' which should be considered as a possible option to explore.
 - To look at approaches for Long Term Conditions in Greater Manchester and the extent to which these could include, or be applied to, those LWC, and to identify resources required to facilitate this.
 - To identify current resources for support/befriending within Greater Manchester
- **To develop a psychological support strategy for patients and carers with input from MC Psychological Support subgroup:**
 - To develop, with professionals "Top 10 things to consider" when supporting patients living with cancer.
 - To identify simple and effective ways for people to use in coping with uncertainty and anxiety and consider how those could be made widely available/promoted
 - To promote regular assessment (as part of HNA and at other interactions) with response to identified need, by any professional who encounters someone LWC
- **To obtain assurance that all organisations and services are able to provide information and access to advice on financial and employment concerns.**
- **To share the important information provided by patients and carers through this exercise within Manchester Cancer and to promote further audit of experience of life after treatment and of living alongside cancer.**

5. Increasing research and innovative practice

5.1 Information

Macmillan awarded Manchester Cancer a “Living With and Beyond Cancer Innovation Fund” in order to generate opportunities for Pathway Boards to develop and test innovative ideas that will improve the outcomes and experience of those who are living with and beyond cancer .

The Innovation Fund was initially set at £90k, but was later increased to £350k. This allowed the majority of the tumour site-specific Pathway Boards to apply for funding, for a variety of initiatives and interventions.

The purpose of the Innovation Fund is to:

- Support and accelerate the adoption of approaches that address cancer survivorship by all Pathway Boards;
- Encourage novel approaches that will meet the needs of existing and future cancer survivors in the Manchester Cancer population; and
- Create opportunities for Manchester Cancer to lead in the development of good practices that are exemplars for national and international cancer services.

5.2 Progress

The Innovation Fund was launched on 1st October 2014, by way of an email to all Pathway Board Directors.

A template application form and accompanying guidance notes were provided, and prospective applicants were encouraged to discuss their ideas with members of the LWBC team. Only members of Manchester Cancer Pathways Boards were eligible to apply for access to the fund.

The fund was promoted further at the Manchester Cancer Living With and Beyond Cancer Pathway Board Education Event, which took place at UHSM on 25th November 2014, and which was attended by 85 delegates, including 45 representatives of the Manchester Cancer Pathway Boards.

The deadline for receipt of draft applications was 31st December 2014. Nineteen draft applications were received and shared with the Assessment Panel, which is comprised of:

- Director of LWBC Pathway Board (Wendy Makin)
- Patient representatives (Sue Taylor and Brian Hixson)
- Macmillan Project Manager for LWBC (Lindsey Wilby)
- Macmillan Development Manager (Julie Atkin-Ward)

- Representative from Trafford CCG, lead cancer CCG for Greater Manchester (Adrian Hackney)
- Associate Director of Manchester Cancer (Tom Pharaoh)

The draft applications were considered at the Assessment Panel's initial meeting on 19th January 2015, after which detailed feedback and critique was provided to all applicants.

The deadline for receipt of final applications was 19th February 2015. Seventeen applications were received, representing 11 Pathway Boards.

The final bids submitted amounted to £509k. The Assessment Panel met for the second time on 24th February 2015 to consider all final applications. The applications were assessed against a set of agreed criteria, which were as follows:

Impact	Proposal is focused on achievable and measurable outcomes, which will improve the lives of people living with and beyond cancer.
Innovation	<p>Proposal is genuinely innovative or takes existing work in a new direction.</p> <p>There may be a proposal to adopt the Recovery Package models in such a way that they meet specific needs of tumour groups and therefore enable implementation.</p> <p>Should also demonstrate an awareness of any work that has already been done in the same area.</p>
Regional	<p>Proposal is applicable (in relation to the cancer type) across the whole of the Manchester Cancer region.</p> <p>Although the project itself may be carried out at a single site, if so the project report should contain recommendations for how the work would be more widely implemented.</p>
Timely	<p>Project can realistically be completed with a report submitted by 30 March 2016. <i>[Later extended to 31st May 2016]</i></p>
Sustainable	<p>Project is designed, where appropriate, to obtain evidence that would provide a case for on-going funding or support from providers and commissioners following the project end date.</p>
Affordable/ value for money	<p>Proposal represents good use of Macmillan funds.</p>
NOT existing work	<p>Proposal should NOT be about supporting existing/on-going projects or activities.</p>

Following consideration against these criteria, 13 of the 17 final applications were approved for funding, totalling £328.4k. All applicants were advised of the outcome of their bids on 11th March 2015.

The applications submitted, and the outcomes for each, are listed in the appendix 3.

Two of the unsuccessful applications are being supported by Manchester Cancer to pursue their objectives via their respective Pathway Boards, and, where possible, to consider alternative sources of funding.

Guidance for project leads was issued in on 1st April 2015, and Project Service Agreements have been prepared, to ensure that all parties have a clear understanding of their respective responsibilities with regard to the running of the projects and ensuring their success.

Projects must be concluded – including the submission of a final project report to Macmillan and Manchester Cancer – by 31st May 2016.

Project leads will report to Manchester Cancer on a quarterly basis throughout the life of the project, and the LWBC team and Pathway Board will provide varying levels of support to each project on the basis of need. A showcase event to share the learning from each of the projects is planned for June 2016.

6. Update from Manchester Cancer board members

6.1 Pennine

The impact on Pennine involvement on the board has enabled progress and implementation of the recovery package. This engagement It has also helped in discussions with the North East Sector locality group, , and has led to their engagement in helping to drive the agenda forward.

Although there seem to be pockets of activity across the Greater Manchester Cancer footprint the impression I get, which may be incorrect, is that much of it does not seem to be as joined up as it could be, especially in terms of commissioner engagement.

I feel that we are in a privileged position at Pennine as LWABC is firmly on the agenda for our commissioners, and also thanks to the funding which Macmillan has provided for a team to help facilitate taking forward implementation.

All positions have now been appointed to the Pennine Acute Hospital Trust (PAHT) LW&BC project team which will support the clinical teams to look at end of treatment summaries and stratifying outpatient follow up. The team leader takes up post on July 6th. A Prostate Cancer UK nurse has been appointed and will be taking up post in Aug 2015 for 18/12. The remit is to look at the support needs of prostate patients on remote monitoring.

The North East Sector clinical commissioning (CCG's) have set up a joint LW&BC board across PAHT and Primary Care in order to dovetail patient care between primary and secondary care and to try to ensure ease of transfer from secondary care into primary care.

The Board meets every 2 months. Primary Care is currently working together to establish what services are currently available and how to develop them for example;

- Oldham CCG has a 1:1 pilot which is due to be evaluated.
- The exercise programme in Bury CCG, Bury exercise and therapy scheme (BEATS), now has LW&BC on its referral criteria.
- Commissioning for quality and innovation (CQUIN) for end of treatment summaries- initially for breast and lung but to be rolled out across more tumour groups in due course.

6.2 Stockport

There is some pilot work on-going within Stockport NHS Foundation Trust to promote the Recovery Package: Specific Holistic Needs Assessment Clinics are being piloted in the community for 2 tumour groups to ensure patients receive dedicated time to discuss their concerns away from a clinical area. Results from pilots like this are useful to share with colleagues on the Pathway Board to generate and discuss ideas.

The Pathway LWABC Board, by publicising its objectives has also motivated members of other pathway boards within the organisation. Members are initiating discussions and plans to consider other aspects of the Recovery Package relevant to their clinical areas.

As LWABC is such a far reaching cross cutting theme across all tumour groups it is important that it continues to work across different levels and forums to generate change. Clinicians need to be engaged and supported so they are motivated and can see the benefits to their patients' experience under their care.

From a personal perspective attending the board has proved supportive and reassuring. Initiating change can often be a challenging process so working with colleagues who may be experiencing similar issues is a bonus. Work streams can be developed and cross organisational collaboration is much more productive.

6.3 UHSM

The Macmillan centre at UHSM was already involved with the recovery package prior to joining the board as a member, but since then, there have been far more developments and the board has helped in the promotion of collaboration and shared learning.

We have just recently delivered a 3rd colorectal health and well-being (H&W) event- the first two strongly involving The Christie in having Ben Heyworth presenting at the first and Dr Wendy Makin at the second under the heading of 'life ahead'. The market place element is organised by the Macmillan cancer information centre UHSM and has proved very popular at all three events.

Our colorectal nurses won the UHSM diamond award for innovation, for their work in the recovery package and it is great to see their work recognised and shine a light on the recovery package. It highlighted the whole team including Mrs Sarah E Duff MD FRCS Consultant General and Colorectal Surgeon. Mrs S Duff is clinical director on the Manchester Cancer colorectal board.

We also organised a collaborative education event with one of the Macmillan learning development managers and cancer lead nurses from Stockport and the local Macmillan development manager- this was very successful. There was a follow up event with to mark/note progress and work on support to take projects forward, there may be further events to link up with Manchester Cancer team members

Being part of the LW&BC Manchester Cancer board, has definitely helped encourage combined working with not only the teams joining together for Health and well-being events- the Centre team at UHSM was also involved in the prostate cancer H&W event at the Christie, but also creating reciprocal support between teams e.g. new walking programmes at the Christie being supported by the learning from UHSM Macmillan Cancer information service(MCISS) walking groups.

It has had a very positive knock on effect for patients too, in that the H&W events at both hospitals have promoted Macmillan Connections- patients visiting the events at UHSM and the Christie have gone on to join Macmillan Connections activities and are realising the benefits of self-management through such activities as our walking groups, yoga group, allotment etc., enhancing confidence, reducing isolation and encouraging physical activity.

We will be taking forward more health and well-being events with other multi-disciplinary teams (MDT's) and I am sure being part of Manchester cancer will help to drive it forward.

6.4 Wigan

Wigan are ready to move with the e-HNAs, just awaiting the order of the tablets, then all of our cancer CNS's will be using them. We are part of the HNA Macmillan pilot which finishes next year.

The first meeting of the LW&BC steering group is in June and will have 2 patient reps on the group in future, the Trust have started a case of need to Macmillan to implement the recovery package for some resourced to help the team to move this on following a similar model Pennine.

The Trust now offers look good feel better programme monthly our first session had over 12 patient attend and have support groups that run bimonthly (Upper GI, Head and Neck, Palliative Care bereavement, Breast, Lung). Further plans are underway to develop Colorectal and Urology. Active livings attend the support groups and are engaged in walking groups.

6.5 East Cheshire

From an East Cheshire perspective, I think the impact of being involved on the pathway board has added weight and credibility to the whole survivorship agenda at our Trust.

Survivorship/LW&BC is now included as an agenda item at our Cancer Communications Meetings and Oncology Meetings - allowing both myself and Karen Buckley to share with our clinical teams and consultants the 'bigger picture' and also to relate to them how we are engaged with this, not only through Manchester Cancer, but also at a local level.

The education event last November was attended by staff from East who were also able to feedback to the wider teams on this important topic.

Health needs assessment (HNAs) are now being completed post treatment in the breast post radiotherapy clinic and in the colorectal BSA (before surgery assessment clinic). Funding has been secured for delivery of the eHNAs across each group starting with Lung.

We now have 4 tumour specific groups for 'Living with and Beyond Cancer' covering Head & Neck, Colorectal, Lung and Breast. Each group meets monthly for a programme of either 6 or 12 months (depending on cancer group and patient feedback) addressing physical activity, management of fatigue, nutrition, breathlessness, mindfulness, management of anxiety etc.

We have yet to arrange a Health and Wellbeing Event involving all teams, but this isn't due to lack of enthusiasm, it is rather due to lack of staff availability at a specific time to host such an event and challenges finding suitable external venues.

We are also currently running a Cancer Rehab exercise programme, having funded a member of our team to gain the Cancer Rehab exercise qualification. This is referring patients to 1-1 sessions and supporting them to reach their own personal physical exercise targets following treatment.

We are also starting to work in partnership with our colleagues at Cheshire East Council and East Cheshire Hospice in the 'Everybody Healthy' campaign.

As cancer has recently been added to the 'long term' conditions which is now included in the referral process to the scheme we, along with GP's, are able to refer patients into a 12 week programme of exercise goal setting and training schemes at any of our local leisure centres for a cost of just £12. Trainers in the Leisure Centres have completed the Cancer Rehab training as mentioned before.

6.6 Christie

Survivorship Network

The Christie Survivorship Network is engaged in a wide range of activities across the hospital, some of which are projects shared within Manchester Cancer. There is a well- established Patient Reference Group that has led on some developments such as the Patient Manifesto and 100 Voices project.

Work in 2014-15 included

- 6 Development of multi-media Patient Information Resources and LWBC section on the Christie website. There are films and podcasts on a variety of topics.
- 7 Health and Wellbeing Events – testing and evaluation, development of professional resources Frequently asked questions(FAQs)
- 8 Rolling out the Life Ahead Plan – via the chemotherapy treatment centre on site; rehabilitation and complementary therapies; radiotherapy. Use of the booklet has been shared with other Trusts and organisations.
- 9 Collaborative working around education and training with local universities – Post graduate certificate in Cancer Survivorship with the University of Salford.
- 10 Establishment of the Lesbian, gay, bi-sexual, transgender (LGBT) Cancer Support Alliance – current project include “Proud2Bsmokefree”, prostate cancer project

Physiotherapy and OT teams are proactive in promoting physical health and well-being:

- In Patient Fatigue classes
- Out Patient Pink Ribbon Pilates class - for breast cancer patients is run weekly by a senior physiotherapist who is also a fully qualified Pink Ribbon instructor.
- Out Patient Lymphoedema support group
- Out Patient ‘Stretch and De stress’ session
- ‘Steps’
- Out Patient Pre- operative Gynaecology School
- Out Patient teenage and young adult (TYA) Body Image and TYA Avascular Necrosis support groups
- 3 Month Supported Self -Management Programme (Innovation fund), is led by The Christie Information Centre and Physiotherapy Department. Patients will be expected to identify goals and walk daily using a pedometer and Macmillan activity diary.

In the City of Manchester, Manchester Cancer Improvement Partnership (MCIP) has a number of work streams. Christie staff from the lung and breast teams are engaged with further development of end of treatment summary information and application of HNA

There are also other Manchester Cancer Innovation Fund innovation projects involving, or led by Christie teams in conjunction with Tumour Pathway Boards.

- Secondary Breast Cancer: this project is based at The Christie but open to all in the Manchester Cancer region, and focuses on developing health and wellbeing events as part of a wider strategy on coping with the uncertainty of a cancer diagnosis and treatment.
- Brain: focuses on how health and wellbeing events can support patients living beyond brain tumours, and includes a training and education component for HCP
- Urology: This project will explore the identification and management of patients at risk of cardiac events and osteoporosis.
- Gynaecology: this project will focus on education and training and include the delivery of an e-learning module for HCPs
- Sarcoma: The 'Plan B' initiative is for patients with life limiting disease. This project will pilot a personalised programme and a framework in which their progress can be shared with family, other patients and their clinical team
- Speech and Language support: focuses on developing a risk stratification model to effectively target support.

1. Objectives for 2015/16

Work will continue with pathway directors and boards to improve the outcome and experience to those living with and beyond cancer. It has been proposed that Manchester Cancer to facilitate the development of a patient reported outcome measures (PROMS) to capture experience of life after cancer treatment and cancer within the population.

There is a specific target to ensure that GPs and patients receive summary information that the conclusion of planned treatment as this is an essential component of the Recovery Package. The Innovation fund projects will be underway with X tumour-specific Boards. LWBC Board will support this work and look to future sharing or development of good practice. Importantly there will be efforts to work with the pathways that did not apply to the fund or were unsuccessful.

Work will focus on how elements such as Health and Well Being activities can be delivered across Manchester Cancer and to a high standard while using resources efficiently.

The Recovery Package Models that are promoted for the conclusion of curative treatment may not always be the best approach for those who face living with cancer, on-going treatment and a less certain future. This is an important area that will be developed in response to the recommendations from the 2014-15 working group.

We will also start work in another important aspect of cancer survivorship: the impact of on-going and long term consequences from treatment, in conjunction with all other Boards.

This work will work with people affected by cancer, draw upon specialist knowledge of specific problems, their likelihood and how these might be identified and managed together with approaches for some of the common and generic issues encountered regardless of type of cancer.

The LWBC 201516 objectives are:

- Benchmarking metrics including 'Life after treatment' audit of patient experience and Recovery Package targets (especially end of treatment summary information)
- Health and Wellbeing model guidance, develop CQUIN and tariff
- Implementation of summative information at conclusion of curative treatment
- Increase usage of care plans: strategies to promote with, and engage patients
- Living with Cancer subgroup recommendations
- Consequences of treatment (COT): for agreed specific COT, baseline mapping and pathways and proposals to develop further 2016-17
- Innovation fund projects: maintain oversight of progress via quarterly reports and plan showcase event to take place in June 2016
- commitment to support lymphoedema, work closely with commissioners on guidance and good practice

Appendix 1 – Pathway Board meeting attendance

NAME	ROLE/ Trust	25th March	15th July	15th Sept	21st Nov	20th Jan	25th March
Wendy Makin	Director/consultant Christie	✓	✓	✓	✓	✓	✓
Kathy Pantelides	AHP/Rehab manager Christie	✓	✓	✓	✓	✓	✓
Ben Heyworth	Survivorship project manager Christie	✓	✓	✓	✓	✓	✓
Claire Higham	Consultant endocrinologist – Christie and Stepping Hill	✓	x	x	x	x	x
Val Goode**	Nurse clinician, Lymphoma team, Christie	✓	x	x	x	x	
Abbas Chittalia	Consultant oncologist (breast and lung)- Christie and Stepping Hill	✓	x	x	✓	✓	·x
Claire Rehan	Clinical Psychologist, Bolton FT	✓	✓	✓	✓	✓	·✓
Pat Jones	Lead cancer nurse, CMFT	✓	✓	x	✓	✓	✓
Pauline West*	Macmillan info and support manager, Trafford	✓	✓	✓	✓		
Janet Parkinson	Macmillan info and support manager, East Cheshire	✓	✓	✓	x	x	x
Karen Buckley	Lead cancer nurse manager, East Cheshire	x	✓	x	x	x	x
Jo Keogh	Strategic cancer lead, PAT	✓	✓	x	x	x	x
Felicity Keeling	Macmillan info and support manager, PAT	✓	✓	✓	x	✓	x
Ian Ainscough	Macmillan info and support manager, SRFT	x	·	·	✓	·	✓
Julie Orford	Lead Macmillan Nurse, UHSM	✓	x	✓	✓	·x	x
Debbie Smith	Macmillan info and support manager, UHSM	✓	x	x	x	✓	x
Karen Livingstone	Physiotherapist breast/lymphedema UHSM	✓	✓	✓	✓	✓	✓
Julie Pieczarka	Macmillan info and support manager, Mid Cheshire	✓	x	x	x	x	x
Vanessa Hickson	Keyworker, Tameside	x	✓	x	✓	·x	x
Beverley Gail Meenan	Macmillan Lead Nurse for Cancer and Palliative Care, SFT	x	x	✓	✓	✓	✓
Julie Atkin-Ward	Macmillan Development Manager	x	✓	✓	x	✓	x
Liane Harris	GP, Cancer Lead Bury CCG	x	✓	✓	x	✓	✓
Rachel Mcmillan	St Ann's Hospice and Neil Cliffe Centre representative	x	✓	✓	x	✓	✓
Ann-Marie Kelly	Patient Information Manager WWL	x	·	✓	✓	·	✓
Sue Taylor	Patient representative	x	✓	✓	x	✓	✓
Brian Hixson	Patient representative	x	·	·	✓	✓	✓

*resigned in December 2014

** resigned in March 2015

Appendix 2 – Pathway Board Annual Plan 2015/16

Pathway Clinical Director:	Dr Wendy Makin	
Pathway Board Members:	Kathy Pantelides Ben Heyworth Claire Higham Val Goode Abbas Chittalia Claire Rehan Pat Jones Pauline West Janet Parkinson Karen Buckley Jo Keogh Felicity Keeling Ian Ainscough Julie Orford Debbie Smith Karen Livingstone Julie Pieczarka Vanessa Hickson Beverley Gail Meenan Julie Atkin-Ward Liane Harris Rachel Mcmillan Ann-Marie Kelly Sue Taylor Brian Hixson	AHP/Rehab manager Christie Survivorship project manager Christie Consultant endocrinologist – Christie Nurse clinician, Lymphoma team, Christie Consultant clinical oncologist (breast and lung) Christie and Stepping Hill Clinical Psychologist, Bolton FT Lead cancer nurse, CMFT Macmillan info and support manager, Trafford Macmillan info and support manager, East Cheshire Lead cancer nurse manager, East Cheshire Strategic cancer lead, PAT Macmillan info and support manager, PAT Macmillan info and support manager, SRFT Lead Macmillan Nurse, UHSM Macmillan info and support manager, UHSM Physiotherapist breast/lymphedema UHSM Macmillan info and support manager, Mid Cheshire Keyworker, Tameside Macmillan Lead Nurse for Cancer and Palliative Care, SFT Macmillan Development Manager GP, Cancer Lead Bury CCG St Ann's Hospice and Neil Cliffe Centre representative Patient Information Manager WWL Patient representative Patient representative
Pathway Manager:	Hodan Noor	
Date agreed by Pathway Board:	June 2015	
Review date:	December 2015	

Summary of objectives

No	Objective	Alignment with Provider Board objectives
1	Working with pathway directors and boards to improve the outcome and experience to those living with and beyond cancer	<ul style="list-style-type: none"> ➤ Improving outcomes, with a focus on survival ➤ Improving patient experience ➤ Delivering high quality, compliant, coordinated and equitable services

Objective 1: Working with pathway directors and boards to improve the outcome and experience to those living with and beyond cancer

<p>Objective:</p>	<ul style="list-style-type: none"> - Benchmarking metrics including 'Life after treatment' audit of patient experience and RP targets - Health and Wellbeing model guidance, develop CQUIN and tariff - Implementation of summative information at conclusion of curative treatment - Increase usage of care plans: strategies to promote with, and engage patients - Living with Cancer recommendations to take forward tbc - Consequences of treatment: for agreed specific COT, baseline mapping and pathways and proposals to develop further 2016-17 - Innovation fund projects: maintain oversight of progress via quarterly reports and plan showcase event Spring 2016
<p>Rationale:</p>	<p><i>What was the Pathway Board's motivation for choosing this objective? What is the expected impact on the quality and experience of patient care and on the health of the wider population?</i></p> <p>The NHS Outcomes Framework 2014-15 makes clear that we have responsibility to support people in recovery from significant illness and also when living with long term conditions, as well as improving survival rates.</p> <p>While better survival remains a priority for cancer, these other aspects increasingly apply as the numbers both of long term survivors increase and also those for whom cancer has become a chronic condition.</p> <p>The Cancer Taskforce has signalled that the next cancer strategy for England 2015-2020 will place increased emphasis on better empowerment of patients in self- managing their condition; in rehabilitation and promotion of healthier lifestyles and promoting return to work.</p> <p>All of these can be influenced through the preparation and approaches that are adopted both through, and beyond, cancer treatment. A core component will be the systematic use of the national 'Recovery Package'* developed through the National Cancer Survivorship Initiative with Macmillan Cancer Support UK. In turn, this will also enable stratified pathways for follow up and surveillance.</p> <p>The Living With and Beyond Cancer Board aims to collaborate with the other tumour-specific pathways to support patients (and those close to them) in this important aspect of care, and to enable GPs and other professionals outside specialist cancer services to be better equipped to support them in secondary and community settings.</p>

	<p>The Board works closely with the Palliative and End of Life Care Board and other groups including psychological support and AHP/rehabilitation.</p>
<p>By (date):</p>	<p><i>What is the target date for completion? If completion is expected beyond 2015/16 what progress is expected in year? If a phased approach is to be taken indicate this here.</i></p> <p>June 2016</p>
<p>Board measure(s):</p>	<p><i>Which of the Pathway Board's key measures will show it that the objective has been met? What are the performance standards that will be expected?</i></p> <ul style="list-style-type: none"> ➤ Benchmarking metrics including 'Life after treatment' audit of patient experience and RP targets ➤ Health and Wellbeing model guidance develop QUIN and tariff ➤ Implementation of end of treatment summaries in at least 3 clinical pathways ➤ Increased usage of care plans overall by 10% NCPES ➤ Innovation fund projects learning report ➤ List of consequences of treatment late effects from all pathways ➤ Recommendations from the Living with Cancer sub group ➤ To review the use and adaptation of the Recovery Package to ensure it meets the needs of patients who are living with cancer <ul style="list-style-type: none"> - Develop models for Health and Well Being events specifically for patients Living With Cancer - To agree with tumour pathway Boards standard practice for provision of summary or update information at regular (at least 4-6 monthly) intervals for those on on-gong treatment pathways - To identify those who may be entering the last year of life to ensure timely Advanced Care Planning and provision for End of Life Care is anticipated in all settings ➤ To influence a process for the above information (summary letters, HNA, ACP) should be shared with all involved professionals- between hospitals, with GP , community team and hospice. ➤ To explore non-clinical models for community-based support for those LWC

	<p>and their carers:</p> <ul style="list-style-type: none"> - Wythenshawe Macmillan centre managed by Manchester City Council (Library service) has developed a model ‘The Case for a Community Based Model’ which should be considered as a possible option to explore. - To look at approaches for Long Term Conditions in Greater Manchester and the extent to which these could include, or be applied to, those LWC, and to identify resources required to facilitate this. - To identify current resources for support/befriending within Greater Manchester <p>➤ To develop a psychological support strategy for patients and carers with input from MC Psychological Support subgroup:</p> <ul style="list-style-type: none"> - To develop, with professionals “Top 10 things to consider” when supporting patients living with cancer. - To identify simple and effective ways for people to use in coping with uncertainty and anxiety and consider how those could be made widely available/promoted - To promote regular assessment (as part of HNA and at other interactions) with response to identified need, by any professional who encounters someone LWC <p>➤ To obtain assurance that all organisations and services are able to provide information and access to advice on financial and employment concerns.</p> <p>➤ To share the important information provided by patients and carers through this exercise within Manchester Cancer and to promote further audit of experience of life after treatment and of living alongside cancer.</p>
<p>Risks to success:</p>	<p><i>What factors will hinder or prevent the Board’s ability to achieve the objective? How will these risks be mitigated?</i></p> <p>None Identified</p>
<p>Support required:</p>	<p><i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i></p> <p>None identified</p>

Work programme		
Action	Resp.	By (date)
Benchmarking metrics including 'Life after treatment' audit of patient experience and RP targets	LW	June 2016
Health and Wellbeing model guidance, develop CQUIN and tariff	All	June 2016
Implementation of summative information at conclusion of curative treatment	All	June 2016
Increase usage of care plans: strategies to promote with, and engage patients	All	June 2016
Living with Cancer recommendations to take forward	All	June 2016
Consequences of treatment: for agreed specific COT, baseline mapping and pathways and proposals to develop further 2016-17	HN	June 2016
Innovation fund projects: maintain oversight of progress via quarterly reports and plan showcase event Spring 2016	LW	June 2016

Manchester Cancer Provider Board objectives

1. Improving outcomes, with a focus on survival

We aim to:

- have a cancer survival rate for all cancers one year after diagnosis that is consistently higher than the England average for patients diagnosed beyond 2012
- have a one-year survival rate higher than 75% for patients diagnosed in 2018
- narrow the gap with Sweden's one-year survival rate from 12% (now) to 6% for patients diagnosed in 2020
- approach Sweden's one-year survival rate by 2025, and
- have greater than 70% of cancer patients diagnosed in 2020 survive at least five years

2. Improving patient experience

We aim to:

- improve year-on-year the patient experience across the region (as measured by the National Cancer Patient Experience Survey), and
- have the best performance in core patient experience questions of any major city area in England by 2015

3. Increasing research and innovative practice

We aim to:

- increase the proportion of patients involved in clinical trials from 30% to more than 40% by 2019

4. Delivering high quality, compliant, coordinated and equitable services

We aim to:

- support our specialist commissioning colleagues to deliver compliance in the four historically non-compliant specialist cancer surgery services (oesophago-gastric, hepato-pancreato-biliary, gynaecology and urology) by December 2015, and
- maintain regional compliance with the national cancer 62-day waiting time target

Appendix 3 Final Applications submitted to the Macmillan/Manchester Cancer Living With and Beyond Cancer Innovation Fund, 2015

Bid ID no.	Pathway	Brief description of proposal	Lead Trust/Pilot Site	Approved for funding by panel?	Total award approved by panel (£000)
01	Head and Neck	Health and Wellbeing events x 4	CMFT	YES	13.7
03	Lung	Wellness programme (equivalent to a Health and Wellbeing event split over two half days)	Tameside	YES	12.8
05	Lung	Mesothelioma: a) Set-up of dedicated mesothelioma MDT, which would then also be used to prepare End of Treatment Summaries. b) Establishment of patient support group c) Cancer nurse-led follow up following active treatment (or if the patient decides against active treatment initially).	UHSM	No	N/A
06	Colorectal	Colorectal CNS group, Health and Wellbeing events, dedicated project management resource.	Based at UHSM, but impacts whole region	YES	35
07	Hepato-pancreato-biliary	Telemedicine/Skype-type service, particularly useful for patients in outlying/rural areas.	East Cheshire	No	N/A
08	LWBC/Sarcoma	Living well with cancer: supported self-managed and personalised integrative regimen for patients living with cancer. Pilot population is Sarcoma.	Christie	YES	59.7 (max – total is subject to further approval)
09	Head and Neck	Risk stratification of AHP input for Head and Neck patients	Christie	YES	30.8
10	LWBC	3-month Self-Management Walking Programme.	Christie	YES	5.4

11	Hepato-pancreato-biliary	An integrated program of nutritional support, exercise and improved general well-being; and screening for anxiety and depression, across the four phases of: p-rehabilitation, enhanced recovery, recovery/enablement and living with and beyond cancer.	CMFT	No	N/A
12	Breast	Secondary breast cancer – Health and Wellbeing Event(s), part of wider strategy on coping with uncertainty.	Based at Christie, but open to patients across the region	YES	20.7
13	LWBC	Community lymphoedema therapist with a role in GP Practice Education in LWBC.	Community	No	N/A
14	Brain	Scoping exercise with patients re: the actual needs of those living beyond brain tumours, with a view to providing appropriate support services in future. Culminating in Health and Wellbeing Event in month 12.	Based at Christie/Salford, but open to whole region	YES	38.8
15	Brain	Training re: care of those living beyond brain metastases (any primary tumour). To include establishing current level of knowledge and confidence amongst wider cancer professionals, provisions of information and support (i.e. by brain cancer specialists to non-brain cancer specialists).	Based at Christie/Salford, but open to whole region	YES	32.6
16	Oesophagus-gastric	Patients with oesophagus-gastric cancer to be referred to Can-Move for a structured exercise plan pre-operatively and post-operatively.	Salford	YES	1.9
17	Gynaecology	Multidisciplinary education event re: awareness of potential CoTs and their management - potentially joint with colorectal and/or urology.	Based at Christie, but open to professionals across the region	YES	34.5
18	Urology	Identification and management of patients at risk of cardiac events and osteoporosis following hormone treatment.	Salford	YES	17.4
19	Urology	A Multidisciplinary Community-Based Uro-Oncology Survivorship Clinic	Salford	YES	25.1
Total:				13/17	£328.4k

