In partnership with MACMILLAN CANCER SUPPORT

NHS Lincolnshire Sustainability and Transformation Partnership

Living With Cancer Strategy for Lincolnshire

2021 – 2023

October 2021

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Version control

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Table of contents

Executive Summary	Page 4
Introduction	Page 7
Our principles and values	Page 9
Our vision 2021 - 2023	Page 11
How will we measure our success?	Page 25
The future: 2023 onwards	Page 26
Appendix 1: LWC report 2019 - 2021	Page 27
Appendix 2: LWC programme 2021 – 2023. Programme Framework , Outcomes Framework and Strategic Action Plan 2021 – 2023	Page 51
Appendix 3: Annie's case study	Page 69
Appendix 4: LWC governance structure	Page 73

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NHS Lincolnshire Sustainability and Transformation Partnership

Executive Summary

Background

There are currently 2.5 million people in the UK living with cancer; this is expected to rise to 5.3 million by 2040[1]. Cancer survival is at its highest ever, with significant improvements made in the last 15 years, and people are now twice as likely to survive at least 10 years after being diagnosed with cancer as they were at the start of the 1970s[2].

In Lincolnshire alone, with our ageing population and with these improvements in diagnosis, treatment and aftercare there are currently over 32,000[3] people living with cancer and this is expected to rise to 45400 by 2030.

The Lincolnshire Living with Cancer programme aims to change and improve the experience of people living with cancer in the county.

Our aim:

'We will develop person-centred, local support for people living with cancer, their carers and significant others in Lincolnshire'

Our objectives are that by May 2023, we will:

- develop end to end integrated support pathways across the statutory and voluntary sectors which will improve outcomes and support people living with and beyond cancer.
- ensure people living with cancer are active participants in supported self- management.
- ensure people delivering health and social care, work in partnership to facilitate supported self- management.
- support the roll out and access to personalised care and personalised follow up pathways of care and support for all people living with and beyond cancer.

[1] Macmillan Cancer Support 2018

[2] Cancer: Then and Now. Diagnosis, treatment and aftercare from 1970 – 2016. Macmillan Cancer Support August 2016

[3] 32,128 Cancer Register figures submitted in the QOF March 2021 return.

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- develop a tested and flexible service delivery model for Lincolnshire.
- support a partnership across all stakeholders to transform cancer care into a whole systems approach which becomes everyday business.
- ensure the programme is co-designed with patients, the public and stakeholders.
- ensure the programme is fully evaluated to measure the impact and outcomes on the experience of people living with cancer, and the workforce, and recommendations for future evaluation and measurement of the programme are delivered.
- ensure there are the right people in the right place with the right skills to provide timely support for people living with cancer across the county.
- ensure the programme aligns and integrates with other strategic, organisational and operational developments locally.
- ensure people living with and beyond cancer experience seamless and co-ordinated pathways of support.

What have we done so far?

We have restored and recovered the programme after the Covid pandemic and secured funding for the programme until March 2023. We have developed a programme framework to deliver the programme across the Lincolnshire system and recruited a 'new' Living with Cancer team.

What are we going to do next?

We will continue to place people at the centre of everything we do and support the Cancer Co-production Groups and Cancer Patient Panel. We will continue to roll out holistic needs assessments, treatment summaries, cancer care reviews and access to health and wellbeing interventions, and personalised follow up pathways in acute care and community for breast, prostate, colorectal, endometrial, lymphoma and skin cancers. We will develop a Triage/Navigate/Refer/Record model which can be used consistently by different staff groups and at different points on cancer pathways. We will develop a 'delivery arm' of the Living with Cancer programme by collaborating with other services and organisations and using existing 'assets', and ensure that we use the evidence we collect to ensure that there is equity across the county. We will explore how to enhance psychological and emotional support and access to physical activity and fatigue management for people living with cancer as these have been highlighted as areas of major concern for people. We will continue to work with Primary Care Networks and Neighbourhood Working teams to make sure we make best use of the services we already have. We will implement our Digital and workforce development plans. We will work towards making the programme 'business as usual' and secure sustainable funding by March 2023.

When are we going to do it by?

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We aim to integrate the Living with Cancer programme with the Lincolnshire Integrated Care System by 2023, so that we can carry on developing personalised care and support for people living with cancer in the future, in collaboration with other programmes and organisations in the county.

Who is going to do it?

The Living with Cancer programme team will work with other teams, programmes and organisations across the county and in different sectors to make sure that all our assets are used in the best way and are joined up, and the right people are in the right place at the right time to support people in a way that is right for them.

Where are we going to do it?

We are going to do this right across the geography of Lincolnshire and across different organisations in all sectors. We will also work with colleagues in different areas to ensure that their patients who live in Lincolnshire are able to access the support they offer, as well as support closer to home.

What will success look like?

We will use both quantitative data and qualitative data to evidence our work, and evaluate the success of the programme in 2023.

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Introduction

There are currently 2.5 million people in the UK living with cancer; this is expected to rise to 5.3 million by 2040[4]. Cancer survival is at its highest ever, with significant improvements made in the last 15 years, and people are now twice as likely to survive at least 10 years after being diagnosed with cancer as they were at the start of the 1970s[5].

In Lincolnshire alone, with our ageing population and with these improvements in diagnosis, treatment and aftercare there are currently over 32,000[6] people living with cancer and this is expected to rise to 45400 by 2030.

In 2017 we adopted 'The Living with and Beyond Cancer Strategy for Lincolnshire 2017 – 2019' (LWC Strategy 1) which set out its aims to change and improve the experience of people living with cancer in the county. This strategy laid the foundations to transform pathways across the health and social care system, and our approach by which we would achieve this. Following this approach the programme work for these two years was been largely 'behind the scenes' working to build the Living with Cancer Team, build system wide relationships, integrating with acute services and Neighbourhood Teams and Voluntary and Community Services, testing potential ways of working and laying firm foundations for the delivery of the programme.

The Living with Cancer Strategy 2019 – 2021 (LWC Strategy 2) built on this work and aimed to test the concept set out in the first strategy. We continued to use a collaborative approach, and worked in partnership with statutory and voluntary organisations representing partners from around the county. Most importantly, we continued to develop our work with patients, their carers and significant others, again from around the county. We identified three projects which supported the roll out of what was called the Recovery Package and personalised follow up pathways.

During this period, the strategic context in which we worked, nationally, regionally and locally, shifted to support integrated systems of working, proactive care, a focus on population health based systems and 'out of hospital' services. In addition, the importance of the NHS model of personalised care became forefront in the delivery of programmes across systems. Our approach was seen to be valid, and we were successful in securing funding from Macmillan Cancer Support to become an

[4] Macmillan Cancer Support 2018
[5] Cancer: Then and Now. Diagnosis, treatment and aftercare from 1970 – 2016. Macmillan Cancer Support August 2016
[6] 32,128 Cancer Register figures submitted in the QOF March 2021 return.

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'Integrated Right by You Test' site in April 2020. We started an evaluation of the programme to date in February 2020.

In March 2020, the Coronavirus pandemic had a huge negative impact on the programme, with staff redeployed and funding withdrawn. However, this period and the learning from the evaluation programme gave us an opportunity to reflect on the direction in which the programme was moving. When the likelihood of funding being reapplied presented itself, we were able to bid for funding from Macmillan with a refreshed programme framework and definitive timeline to achieve what we initially set out to achieve in 2016. This is; not creating a new service, but rather full integration of the programme within the health and social care system in Lincolnshire, with an emphasis on the use of existing assets, to ensure people receive their support closer to home, in a way that reflects what is important to them.

The Living with Cancer Strategy 2021 – 2023 uses a different format from the first two strategies. The strategy format is shorter and demonstrates how we aim to meet the priorities of the various strategic and policy drivers, funders and organisations which influence the work of the programme. Most importantly though, it shows how we aim to realise the changes that people living with cancer in the county would like to see, and were the basis for our strategic priorities in LWC Strategies 1 and 2.

The programme is entering the final phase of substantial external funding, and therefore this strategy also focusses on succession and sustainability planning post 2023, so that we can continue to support people living with cancer in the best way for each individual, in the best place, at the right time.

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Our Principles and Values

The Living with cancer programme remains a collaborative approach, and continues to adopt the following guiding principles and values both for the programme and those involved. However, they have been made more robust by the accelerated development of Integrated Care Systems nationally (NHS Long Term Plan), regionally (Macmillan and East Midlands Cancer Alliance) and locally (Lincolnshire ICS).

- We will place the person at the centre of everything we do.
- The programme will be developed using a whole person, whole pathway, and whole system approach.
- The programme will fully align with existing and new systems.
- The programme will take account of 'place', in that it will promote and develop services which will support people in the place of their choice.
- The programme will embrace innovation.
- The programme will promote the following Self-Care principles:
    - The community is the heart of the 'neighbourhood team'.
    - The approach involves all ages and is not just focused on people already receiving health or care services.
    - The approach builds on the assets that already exist in the community.
    - The community are equal partners in changing behaviours, building resilience and providing mutual support.
    - Staff involved in neighbourhood teams have an equal journey in changing behaviours, building resilience and providing mutual support to each other. [7]
- The programme will adopt an Asset Based Community Development approach, the elements of which are to:
    - Identify and make visible the health enhancing assets in a community. A community can be place based, or a community of interest, or a community of patients, or a health and social care based community.
    - See individuals and communities as the co-producers of health and wellbeing rather than the recipients of services which will move individuals and communities from passive recipients of services to active participants in their health and care.
    - Promote community networks, relationships and friendships that provide caring, mutual help and empowerment.

[7] Lincolnshire Sustainable Services Review 11th November 2013: A Blueprint for Future Health and Care Services in Lincolnshire.

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- Identify what has the potential to improve health and wellbeing.
- Supports individual's health and wellbeing through self-esteem, coping strategies, resilience, skills, relationships, friendships, knowledge and personal resources.
- Empower communities to control their futures and create tangible resources such as services, funds and buildings.

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Our vision 2021 – 2023

'We will develop person-centred, local support for people living with cancer, their carers and significant others in Lincolnshire'

To achieve this, we will:

- ***develop end to end integrated support pathways across the statutory and voluntary sectors which will improve outcomes and support people living with and beyond cancer.***
- ***ensure people living with cancer are active participants in supported self- management.***
- ***ensure people delivering health and social care, work in partnership to facilitate supported self- management.***
- ***support the roll out and access to personalised care and personalised follow up pathways of care and support for all people living with and beyond cancer.***
- ***develop a tested and flexible service delivery model for Lincolnshire.***
- ***support a partnership across all stakeholders to transform cancer care into a whole systems approach which becomes everyday business.***
- ***ensure the programme is co-designed with patients, the public and stakeholders.***
- ***ensure the programme is fully evaluated to measure the impact and outcomes on the experience of people living with cancer, and the workforce, and recommendations for future evaluation and measurement of the programme are delivered.***
- ***ensure there are the right people in the right place with the right skills to provide timely support for people living with cancer across the county.***
- ***ensure the programme aligns and integrates with other strategic, organisational and operational developments locally.***
- ***ensure people living with and beyond cancer experience seamless and co-ordinated pathways of support.***

The Lincolnshire Living with Cancer (LWC) Programme is a complex programme with many interdependencies, which aims to meet objectives set locally, regionally and nationally and from across sectors

In developing this strategy, we have taken the objectives that we need to meet from our different policy and strategic drivers and stakeholders, and using the LWC approach, show how we will meet these objectives.

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More importantly, however, we have also shown how each strategic objective will help us make the changes that people living with cancer in Lincolnshire would like to see and that are reflected in the Living with Cancer strategic priorities.

These priorities are:

Information governance – people get very fed up with having to give their information time and time again, so we're looking at ways to stop this happening.

Joined up pathways – we're going to look at the way people move through their diagnosis and treatment, and what happens after treatment, and we're going to make the processes smoother, and also put in support so that people don't miss appointments.

Integration – we have been told that sometimes different services don't work together very well, so we're working with other programmes to ensure that everyone works together more readily. They've told us that sometimes organisations don't communicate very well between themselves either.

Workforce – we're going to make sure that we support our workforce during this programme. We're also going to look at volunteer and peer support services, and how they can be involved too.

Communication and conversations – people have told us that sometimes the communication between professionals and themselves could be clearer.

Information, advice and support – many people have said to us that they just don't know what's out there to support them, and don't know where to go to get information, advice and support, so we're looking at ways in which we can make sure that everyone (and this includes health and social care professionals) knows where to go for what they need.

Support services – we know that there are a lot of amazing support services in Lincolnshire, but we also know that there are gaps. So we're going to look at ways in which we can use the services we already have, make them stronger and start new services to help fill the gaps. Many people have said that the psychological and emotional impact of cancer is not well recognised, and more could be done to support this.

Equity – we know that, at the moment, where you live in Lincolnshire can have an impact on the support you can get, so we are looking at ways in which people in all parts of the county can access support more easily.

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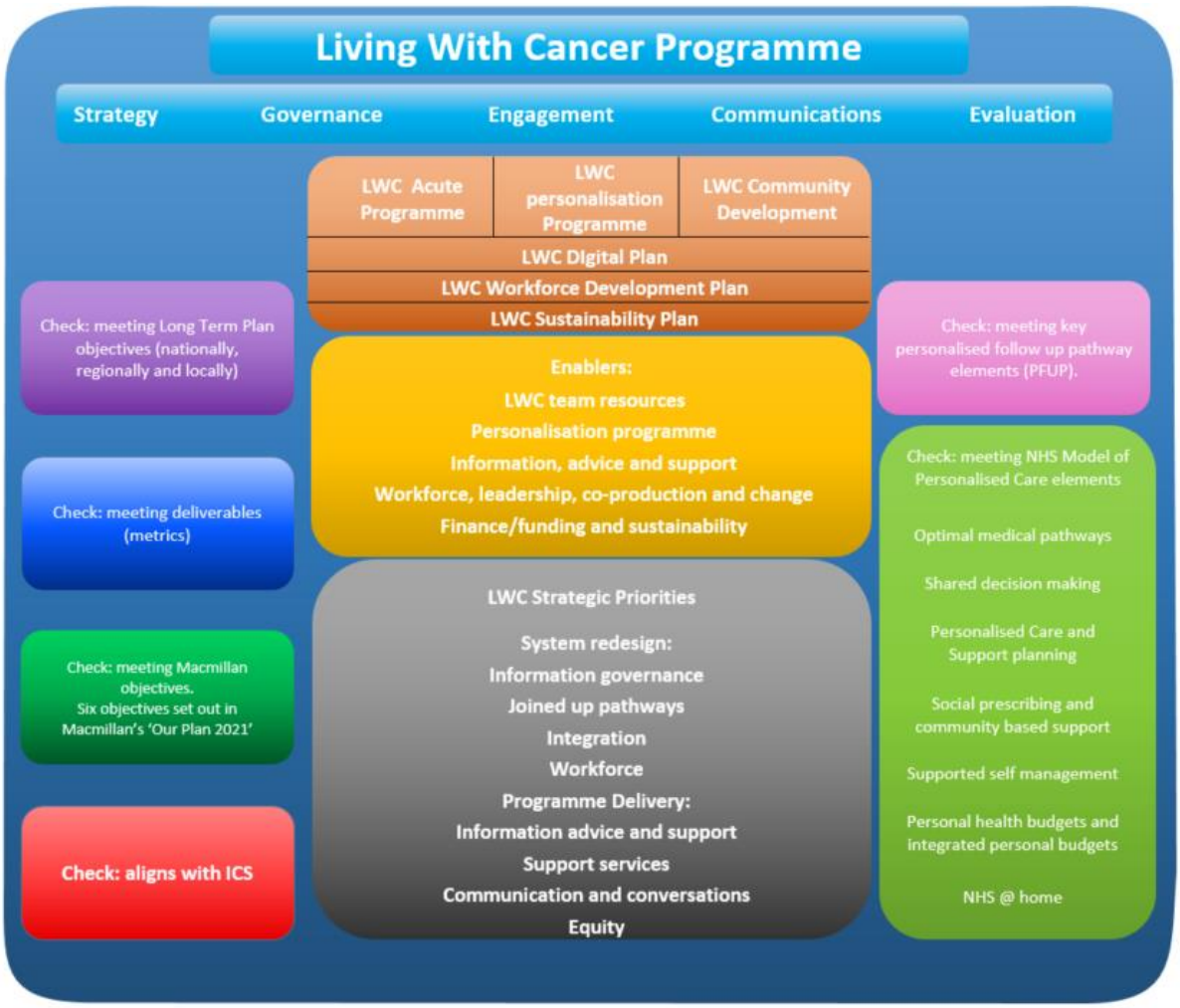

Living with Cancer Programme Outcomes – set at the beginning of the programme

Outcome	**To do this we will:**	**This will help us meet these LWC strategic priorities:**
1. Develop end to end integrated support pathways across the statutory and voluntary sectors which will improve outcomes and	• Develop personalised follow up pathways for breast, prostate, colorectal, endometrial and two other cancers by 2022. • Work with the East Midlands Cancer Alliance to make sure that clinically agreed personalised follow up pathways are implemented in Lincolnshire, in a way that is appropriate to the needs of Lincolnshire residents.	Information governance. Joined up pathways.

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support people living with and beyond cancer	• Use this learning to develop personalised follow up pathways for other cancers. • Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks. • Implement all four living with cancer interventions: holistic needs assessments, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to take account of population needs.	
2. People living with and beyond cancer are active participants in supported self-management.	• Make sure that people have access to reliable information and advice about local support services in a format that meets their needs, including digital solutions. • Make sure that people can access a full range of services that support active self-management by developing and implementing a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Make sure that people's needs are identified in a proactive way by implementing holistic needs assessments and personalised care plans • Use existing assets to make sure those different levels of need in health and wellbeing are catered for, starting at self-care, all the way through to professionally led support. If there are gaps, we will explore ways of filling those gaps.	Information advice and support. Support services. Equity.
3. People delivering health and social care, work in partnership to facilitate supported self- management.	• Align our work with the Lincolnshire Personalisation Programme. • Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks. • Identify different workforces that support people living with cancer, and using our People Plan, make sure they have the skills, knowledge and confidence to support people living with	Integration. Workforce. Communication and conversations.

	cancer.	
4. Support the roll out and access to personalised care and personalised follow up pathways of care and support for all people living with and beyond cancer.	• Work with the East Midlands Cancer Alliance to make sure that clinically agreed personalised follow up pathways are implemented in Lincolnshire, in a way that is appropriate to the needs of Lincolnshire residents. • Develop personalised follow up pathways for breast, prostate, colorectal, endometrial and two other cancers by 2022. • Use this learning to develop personalised follow up pathways for other cancers. • Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks. • Implement all four living with cancer interventions: holistic needs assessments, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to take account of population needs.	Joined up pathways. Information advice and support. Support services. Equity.
5. A tested and flexible service delivery model is operational in Lincolnshire.	• Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Work with existing service delivery providers to come up with innovative delivery solutions for example the Fighting Fit Programme.	Support services. Equity.
6. A partnership across all stakeholders is established to transform cancer care into a whole systems approach which becomes everyday business.	• Integrate the Living with Cancer programme into the Lincolnshire Integrated Care System by 2023. • Work with other long term condition programmes and the Lincolnshire Personalisation Programme to come up with a consistent model of support which can be used across different condition pathways, with flexibility to support the particular needs of people living with cancer.	Information governance. Joined up pathways. Integration. Workforce. Communications and conversations. Equity.
7. The programme is co-designed with patients, the public	• Continue to support the Macmillan Living with Cancer Co-production Group and make sure that they are able to co-produce parts of the	Equity.

and stakeholders.	programme that are meaningful to them. • Support the establishment of new LWC Co-Production groups in different parts of the county, and with different cohorts of patients. • Develop a refreshed Living with Cancer communications and engagement plan so that people can be involved in the programme. • Work with the ULHT Expert by Experience Programme and patient Experience team to establish a Cancer Patient Panel.	
8. The programme is fully evaluated to measure the impact and outcomes on the experience of patients, carers and significant others, and the workforce, and recommendations for future evaluation and measurement of the programme are delivered.	• Implement the recommendations of and build on the Living with Cancer Evaluation Programme carried out in 2020 • Carry out a further evaluation at the end of the external funding in 2023. • Ensure that recommendations from the Quality of Life and National Cancer Patients' Experience Surveys are carried out.	Integration. Equity.
9. There are the right people in the right place with the right skills to provide timely support for people living with and beyond cancer across the county.	• Develop a Living with Cancer People Plan and make sure it aligns with the Lincolnshire ICS People Plan. • Make the most of our existing workforces, identify their needs, and make sure they have the skills, knowledge and confidence to support people living with cancer. • Support the creation and longevity of new roles if necessary.	Workforce. Equity.
10. The programme aligns and integrates with other strategic, organisational and operational developments locally.	• Work with other long term condition programmes and the Lincolnshire Personalisation Programme to develop a consistent model of support which can be delivered across the system, but is flexible enough to support people living with cancer in different communities. • Integrate the Living with Cancer programme into the Lincolnshire Integrated Care System by	Information governance. Integration.

	2023. • Work closely with Macmillan Cancer Support, East Midlands Cancer Alliance and NHS England to make sure we meet local, regional and national objectives. • Make the most of our digital assets, and make sure everything we do aligns with the Lincolnshire ICS digital plan.	
11. People living with and beyond cancer experience seamless and co-ordinated pathways of support.	• Develop personalised follow up pathways for breast, prostate, colorectal, endometrial and two other cancers by 2022. • Work with the East Midlands Cancer Alliance to make sure that clinically agreed personalised follow up pathways are implemented in Lincolnshire, in a way that is appropriate to the needs of Lincolnshire residents. • Use this learning to develop personalised follow up pathways for other cancers. • Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks. • Implement all four living with cancer interventions: holistic needs assessments, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to take account of population needs. • Integrate the Living with Cancer programme into the Lincolnshire Integrated Care System by 2023.	Information governance. Joined up pathways. Integration. Workforce. Information advice and support. Support services. Communications and conversations. Equity.

Macmillan objectives

Objective	**To do this we will:**	**This will help us meet these LWC strategic priorities:**
1. We want everyone with cancer to know	• Work with the Macmillan Cancer Information and Support Service in our three hospital sites to promote and raise awareness of the support	Information, advice and support.

that they can turn to Macmillan and how we can help from the moment they are diagnosed	available. • Work with other Macmillan services, such as the Macmillan Direct Volunteer Service, to ensure that people are aware of the service, and know how they can access them. • Ensure that the LWC digital offer links to Macmillan on-line services. • Promote Macmillan and the MICSS widely through our Communications and Engagement Plan	
2. We want everyone to have a conversation about all their needs and concerns, and get the support that's right for them	• Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks. • Implement all four living with cancer interventions: holistic needs assessments, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to take account of population needs. • Make sure that everything we do aligns to the NHS model of personalisation.	Communication and conversations.
3. We want everyone to have their vital needs met by high quality services	• Implement all four living with cancer interventions: holistic needs assessments, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to take account of population needs.	Support services.
4. More people are inspired to give to Macmillan so we can continue to be there for people when they need us most	• Develop our Volunteer Plan as part of the LWC Workforce Plan, and make sure it aligns with Macmillan's volunteer services in Lincolnshire. • Promote Macmillan and the Macmillan Cancer Information and Support Service widely through our Communications and Engagement Plan. • Continue to support the Macmillan Living with Cancer Co-production Group and make sure that they are able to co-produce parts of the programme that are meaningful to them.	Workforce.
5. We want to	• Develop and implement a consistent model of	Joined up pathways.

improve the key processes which support Macmillan to do its work as efficiently and effectively as possible	triage/navigate/refer/record which can be delivered in a variety of settings.	Integration.
6. We will reflect and represent the communities we serve in everything we do to support everyone living with cancer	• Work with other long term condition programmes and the Lincolnshire Personalisation Programme to develop a consistent model of support which can be delivered across the system, but is flexible enough to support people living with cancer in different communities. • Integrate the Living with Cancer programme into the Lincolnshire Integrated Care System by 2023. • Make sure that the data we collect is used to bring our programme to the people and communities that need it most, and that it's the best version of the programme for them.	Equity.

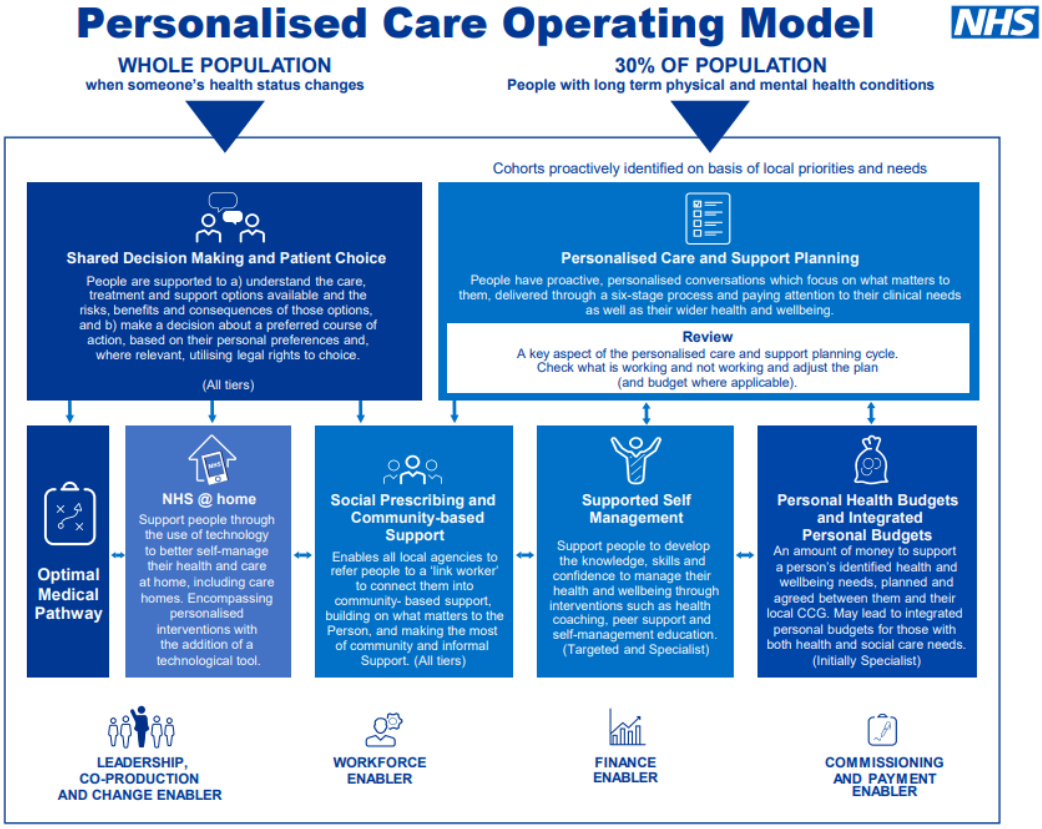
NHS, East Midlands Cancer Alliance and Lincolnshire Long Term Plan Priorities

Objective	**To do this we will:**	**This will help us meet these LWC strategic priorities:**
Agree clinical protocols for personalised stratified follow up (PSFU) pathways in at least three additional cancer types by April 2022, and fully implement at least one of the three, in addition to the existing requirement for PSFU to be implemented with	• Develop personalised follow up pathways for breast, prostate, colorectal, endometrial and two other cancers by 2022. • Work with the East Midlands Cancer Alliance to make sure that clinically agreed personalised follow up pathways are implemented in Lincolnshire, in a way that is appropriate to the needs of Lincolnshire residents. • Work with the East Midlands Cancer Alliance to make sure that clinically agreed personalised follow up pathways are implemented in Lincolnshire, in a way that is appropriate to the needs of Lincolnshire residents. • Use this learning to develop personalised follow up pathways for other cancers.	Joined up pathways. Integration.

digital remote monitoring systems (RMS) in breast, colorectal and prostate.	• Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks.	
Ensure the four main personalised care interventions (personalised care and support planning based on HNA, health and wellbeing information and support, end of treatment summary and cancer care review) are available for all cancer patients.	• Implement all four living with cancer interventions: holistic needs assessments, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to take account of population needs. • Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks. • Make sure that people have access to reliable information and advice about local support services in a format that meets their needs including digital solutions. • Make sure that people can access a full range of services that support active self-management by developing and implementing a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Make sure that people's needs are identified in a proactive way by implementing holistic needs assessments and personalised care plans • Use existing assets to make sure that different levels of need in health and wellbeing are catered for, starting at self-care, all the way through to professionally led support. If there are gaps, we will explore ways of filling those gaps.	Information governance. Joined up pathways. Integration. Workforce. Information advice and support. Support services. Communications and conversations. Equity.
Promote and support the delivery of the Cancer Quality of Life Survey to achieve a response rate of at least 50%	• Work with ULHT to promote the QoL survey with Lincolnshire patients. • Work with ULHT, Primary Care and community based services to ensure that recommendations from the Quality of Life Survey are carried out.	Equity.

by April 2022 and use data to inform service improvement.		
Support the implementation of the 2021 National Cancer Patient Experience Survey (CPES) and the new under-16 Cancer Patient Experience Survey.	• Work with ULHT to promote the National Cancer Patients' Experience Surveys with Lincolnshire patients. • Work with ULHT, Primary Care and community based services to ensure that recommendations from the National Cancer Patients' Experience Surveys are carried out.	Equity.

Key Elements of Personalised Follow up Pathways by aligning to NHS Personalisation Model



Element	**To do this we will:**	**This will help us meet these LWC strategic priorities:**

Shared decision making	• Identify different workforces that support people living with cancer, and using our People Plan, make sure they have the skills, knowledge and confidence to support people living with cancer to participate in shared decisions in an appropriate way. • Develop a refreshed Living with Cancer communications and engagement plan so that people know more about shared decision making. • Work with other programmes, for example Public Health, to support the improvement of health literacy in the county.	Workforce. Information advice and support. Communications and conversations.
Personalised care and support planning	• Implement all four living with cancer interventions including holistic needs assessments and personalised care and support plans. • Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks. • Make the most of our digital assets, and make sure everything we do aligns with the Lincolnshire ICS digital plan to ensure that holistic needs assessments and personalised care and support plans are available to key workers in other parts of the system.	Information governance. Communications and conversations.
Optimal medical pathways	• Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks. • Develop personalised follow up pathways for breast, prostate, colorectal, endometrial and two other cancers by 2022. • Use this learning to develop personalised follow up pathways for other cancers. • Work with ULHT, Primary Care and community based services to ensure that recommendations from the National Cancer Patients' Experience Surveys are carried out.	Joined up pathways.
NHS @ home	• Make the most of our digital assets, and make sure everything we do aligns with the Lincolnshire ICS digital plan.	**Information, advice and support** **Communication and conversations**

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		Equity
Social prescribing and community based support	• Align our work with the Lincolnshire Personalisation Programme. • Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks. • Make sure that people have access to reliable information and advice about local support services in a format that meets their needs, including digital solutions. • Make sure that people can access a full range of services that support active self-management by developing and implementing a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Use existing assets to make sure that different levels of need in health and wellbeing are catered for, starting at self-care, all the way through to professionally led support. If there are gaps, we will explore ways of filling those gaps.	Information governance. Joined up pathways. Integration. Workforce. Information advice and support. Support services. Communications and conversations. Equity.
Supported self-management	• Make sure that people have access to reliable information and advice about local support services in a format that meets their needs, including digital solutions. • Make sure that people can access a full range of services that support active self-management by developing and implementing a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings. • Make sure that people's needs are identified in a proactive way by implementing holistic needs assessments and personalised care plans • Use existing assets to make sure that different levels of need in health and wellbeing are catered for, starting at self-care, all the way through to professionally led support. If there are gaps, we will explore ways of filling those gaps	Information governance. Information advice and support. Support services. Equity.
Personal health budgets (PHBs) and	• We will work with the Continuing Health Care Team and other teams in Lincolnshire, to	

integrated personal budgets (IPBs)	explore ways in which people living with cancer can access PHBs and IPBs.	

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How will we measure our success?

There are a number of targets that we have to achieve between 2021 and 2023 (our deliverables). These have been set by NHS England.

- Agree clinical protocols for personalised stratified follow up (PSFU) pathways in at least three additional cancer types by April 2022, and fully implement at least one of the three, in addition to the existing requirement for PSFU to be implemented with digital remote monitoring systems (RMS) in breast, colorectal and prostate.
- Ensure the four main personalised care interventions
    - Personalised Care and Support Planning (PCSP) based on HNA. Maximise take up and quality of PCSP through the use of COSD data reports, educational offers and quality improvement tools.
    - Health and Wellbeing Information and Support
    - End of Treatment Summary
    - Cancer Care Review are available for all cancer patients.
- Promote and support the delivery of the Cancer Quality of Life Survey to achieve a response rate of at least 50% by April 2022 and use data to inform service improvement.
- Support the implementation of the 2021 National Cancer Patient Experience Survey (CPES) and the new under-16 Cancer Patient Experience Survey.

We will use quantitative and qualitative data to evidence meeting these deliverables.
We will measure our success against these, and also carry out a self-assessment to see whether we have met the 11 outcomes set in 2017 at the beginning of the programme. In addition, we will carry out another evaluation at the end of the programme.

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The future: 2023 onwards

Throughout the next 2 years we will ensure that we are aligning everything we do with the Lincolnshire Integrated Care System. We will do this so that the transformation we have realised and the work that we have done since 2016 can be carried on sustainably and in the best way for people living with cancer in the county. We will:

- Work with other long term condition programmes and the Lincolnshire Personalisation Programme to develop a consistent model of support which can be delivered across the system, but is flexible enough to support people living with cancer in different communities, and uses our existing assets.
- Integrate the Living with Cancer programme into the Lincolnshire Integrated Care System by 2023.

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Appendix 1: LWC Report 2019 – 2021

Overview of progress delivering the Living with Cancer Strategy 2019 – 2021

In the Living with Cancer (LWC) Strategies 2017 – 2019 and 2019 - 2021 we set out our approach and ambitions to change the face of holistic support for people living with cancer in Lincolnshire.

Our approach was driven by policy and strategy nationally, regionally and locally:

2017 - 2019

- NHS 5 year forward view (5YFV).
- 'Achieving World Class Cancer Outcomes'[8].
- NHS England Living with Cancer Programme.
- Lincolnshire Sustainability and Transformation Plan (STP).
- Lincolnshire Cancer Improvement Plan 2016.
- Macmillan's nine outcomes – the things that matter most to people with cancer.
- Patients' experience.

2019 - 2021

National

- NHS Long Term Plan 2019.
- NHS General Practice Forward View 2016.
- 'Achieving World Class Cancer Outcomes'[9].
- NHS England Living with Cancer Programme.
- Macmillan Cancer Support 'Our Strategy 2019 – 2021'.
- Universal Personalised Care – Implementing the Comprehensive Model NHSE January 2019.
- NICE Evidence Standards Framework for Digital Health Technologies 2019.

Regional

- East Midlands Cancer Alliance Living with Cancer priorities.

[8] **ACHIEVING WORLD-CLASS CANCER OUTCOMES** A Strategy for England 2015-2020 – The Independent Cancer Taskforce Report 2015

[9] **ACHIEVING WORLD-CLASS CANCER OUTCOMES** A Strategy for England 2015-2020 – The Independent Cancer Taskforce Report 2015

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- Macmillan in the Midlands GP Strategy.

Local

- Lincolnshire Sustainability and Transformation Plan.
- Lincolnshire Integrated Community Care plan.
- Lincolnshire Cancer Transformation Plan 2019.

More importantly, however, our approach was driven by people in Lincolnshire living with cancer. It was from their input into the LWC Strategy 2017 - 2019 development which defined our strategic themes which were and remain:

- Information governance
- Joined up pathways –we have been told that pathways into and through, and.
- Integration –Workforce Communications and conversations
- Information, advice and support services
- Equity

During the period that the Living with Cancer strategy 2019 - 2021 was 'live' we made progress towards meeting our strategic outcomes which were and remain:

1. We will develop end to end integrated support pathways across the statutory and voluntary sectors which will improve outcomes and support people living with cancer.
2. People living with cancer are active participants in supported self- management.
3. People delivering health and social care, work in partnership to facilitate supported self-management.
4. We will support roll out and access to the Recovery Package (now Personalised Care and Support) and personalised follow up pathways of care and support for all people living with cancer.
5. A tested and flexible service delivery model is operational in Lincolnshire.
6. A partnership across all stakeholders is established to transform cancer care into a whole systems approach which becomes everyday business.
7. The programme is co-designed with patients, the public and stakeholders.
8. The programme is fully evaluated to measure the impact and outcomes on the experience of patients, carers and significant others, and the workforce, and recommendations for future evaluation and measurement of the programme are delivered.
9. There are the right people in the right place with the right skills to provide timely support for people living with cancer across the county.
10. The programme aligns and integrates with other strategic, organisational and operational developments locally.

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11. People living with cancer experience seamless and co-ordinated pathways of support.

We have reviewed our work which has been guided by these strategies, and on reflection, and in the light of the changing health and care environment, changing strategic context and the impact of the Coronavirus pandemic, we have learned that:

- Our strategic themes, aim and objectives are a functional framework for the programme and guide our work well. They are still relevant and can remain unchanged into the next phase of the programme.
- Proof of concept projects and development work to align with the emerging Integrated Care System requires reassessment. The programme was in danger of developing into another 'service' and therefore true integration and use of existing assets was not being realised. Our asset based community development approach is valid; we are committed to using what we already have rather than setting up new services in isolation.
- We have seen some behavioural change in organisations as we move towards integrated system working.
- Behaviour change in individuals to move towards active self-management needs to be supported.
- The Acute and Community Facilitators' roles in supporting our approach to building relationships and supporting behaviour change are vital to the programme, however support for the transition of people between acute and community support still requires improvement, and needs to be a work stream in its own right.
- Our work to support co-production is innovative and supports the ambitions for the NHS Long Term Plan. The Living with Cancer Co-production Group needs to remain if co-production and patient experience is to remain at the heart of the programme.
- A collaborative approach to supporting people living with cancer across the system is vital to successfully sustain change and achieve true transformation.
- Digital solutions and Workforce Development are integral to each part of the programme, are vital to the success of the programme and therefore need implementation plans in their own right.
- The programme has, up until now, relied entirely on external funding from Macmillan and the East Midlands Cancer Alliance and its workforce all have fixed term roles. This needs to stop. The programme as it stands at the moments needs an end date with succession plans and sustainable substantive funding.

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What is the current Lincolnshire picture and what has changed?

Strategic context

On 1st April 2020, the four Clinical Commissioning Groups (CCG) in Lincolnshire merged into one CCG; Lincolnshire Clinical Commissioning Group.

On 11 February 2021, the Department of Health and Social Care (DHSC) published its legislative proposals for a new Health and Care Bill, 'Integration and Innovation: working together to improve health and social care for all' (the White Paper). The plan is to implement these proposals in 2022.

Living with Cancer and cancer prevalence, demographics and patient experience

In Lincolnshire there are currently 32,128 people living with cancer, this is an increase from 27500 in 2017.
Cancer incidence rate per 100,000 registered population in Lincolnshire, by type of disease and CCG, all ages.

Incidence

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	Incidence Rate per 100,000 Registered Population						
CCG / Year	2013	2014	2015	2016	2017	2018	Trend
All cancers							
NHS Lincolnshire East CCG	592.0	664.7	625.7	610.6	609.1	615.5	
NHS Lincolnshire West CCG	604.7	582.6	592.0	589.8	597.8	605.2	
NHS South Lincolnshire CCG	643.1	580.3	582.6	623.8	549.3	593.6	
NHS South West Lincolnshire CCG	637.4	646.1	646.0	584.4	614.1	671.5	
Lincolnshire	619.3	618.4	611.6	602.1	592.6	621.4	
England	631.7	620.4	616.9	612.7	601.9	612.9	
Prostate							
NHS Lincolnshire East CCG	169.9	185.2	176.2	166.8	163.5	190.3	
NHS Lincolnshire West CCG	183.0	167.3	189.1	175.2	164.4	176.0	
NHS South Lincolnshire CCG	250.7	177.1	185.9	201.8	182.3	226.5	
NHS South West Lincolnshire CCG	234.1	224.7	174.3	168.0	173.0	246.9	
Lincolnshire	209.4	188.6	181.3	178.0	170.8	209.9	
England	193.5	183.3	182.3	178.6	175.6	204.1	
Breast							
NHS Lincolnshire East CCG	147.9	206.5	178.1	158.7	179.9	157.0	
NHS Lincolnshire West CCG	163.2	156.3	166.7	165.3	170.8	178.2	
NHS South Lincolnshire CCG	197.3	167.5	135.5	189.9	139.0	149.9	
NHS South West Lincolnshire CCG	126.3	177.8	233.5	135.0	184.8	223.6	
Lincolnshire	158.7	177.0	178.5	162.2	168.6	177.2	
England	171.1	174.0	170.6	168.0	166.2	170.8	
Lung							
NHS Lincolnshire East CCG	71.9	79.0	78.8	86.7	82.1	84.4	
NHS Lincolnshire West CCG	65.3	69.3	64.6	61.8	72.8	74.8	
NHS South Lincolnshire CCG	54.7	70.8	66.2	77.4	63.1	56.3	
NHS South West Lincolnshire CCG	67.6	72.7	56.4	73.7	79.8	59.6	
Lincolnshire	64.9	73.0	66.5	74.9	74.5	68.8	
England	80.6	79.9	79.1	79.4	77.8	75.8	
Colorectal							
NHS Lincolnshire East CCG	74.1	76.1	71.2	67.5	68.3	74.1	
NHS Lincolnshire West CCG	73.9	65.5	68.4	73.7	74.0	60.9	
NHS South Lincolnshire CCG	80.5	68.8	63.9	75.5	65.0	64.6	
NHS South West Lincolnshire CCG	86.3	63.8	80.3	59.7	66.2	80.1	
Lincolnshire	78.7	68.6	71.0	69.1	68.4	69.9	
England	72.8	71.3	71.6	70.7	68.8	69.0	

Source: cancerdata.nhs.uk. All cancers (ICD-10 codes C00-C97), breast cancer (females only) (ICD-10 code C50), prostate cancer (males only) (ICD-10 code C61), lung cancers (ICD-10 codes C33-C34) and colorectal cancers (ICD-10 codes C18-C20).

The above table shows number of Incidences per 100 000 Registered population. Rates have been directly age standardised to allow comparison between varying CCG populations.

Diagnoses

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CCG / Year	Instances of Diagnosis 2013	2014	2015	2016	2017	2018	Trend
All cancers							
NHS Lincolnshire East CCG	1,603	1,824	1,743	1,743	1,773	1,822	
NHS Lincolnshire West CCG	1,323	1,307	1,346	1,372	1,420	1,460	
NHS South Lincolnshire CCG	986	913	940	1,019	917	1,016	
NHS South West Lincolnshire CCG	802	832	852	782	837	939	
Lincolnshire	1,179	1,219	1,220	1,229	1,237	1,309	
England	301,698	302,460	305,634	308,633	309,453	320,395	
Prostate							
NHS Lincolnshire East CCG	225	253	242	238	240	284	
NHS Lincolnshire West CCG	191	177	204	194	186	205	
NHS South Lincolnshire CCG	182	133	144	160	147	187	
NHS South West Lincolnshire CCG	140	140	110	111	116	169	
Lincolnshire	185	176	175	176	172	211	
England	42,047	40,847	41,480	41,460	41,825	49,810	
Breast							
NHS Lincolnshire East CCG	200	285	251	226	260	225	
NHS Lincolnshire West CCG	189	186	202	200	210	221	
NHS South Lincolnshire CCG	160	138	116	161	121	132	
NHS South West Lincolnshire CCG	84	120	161	92	129	161	
Lincolnshire	158	182	183	170	180	185	
England	44,883	46,255	45,952	45,828	45,911	47,697	
Lung							
NHS Lincolnshire East CCG	200	219	224	253	250	259	
NHS Lincolnshire West CCG	145	156	145	144	174	182	
NHS South Lincolnshire CCG	85	113	108	129	107	99	
NHS South West Lincolnshire CCG	87	93	74	99	110	85	
Lincolnshire	129	145	138	156	160	156	
England	7,641	38,117	38,379	39,229	39,500	39,290	
Colorectal							
NHS Lincolnshire East CCG	205	212	207	196	201	224	
NHS Lincolnshire West CCG	163	146	155	173	177	149	
NHS South Lincolnshire CCG	124	109	103	124	108	112	
NHS South West Lincolnshire CCG	108	82	107	79	90	111	
Lincolnshire	150	137	143	143	144	149	
England	34,399	34,441	35,184	35,373	35,157	35,958	

All cancers (ICD-10 codes C00-C97), breast cancer (females only) (ICD-10 code C50), prostate cancer (males only) (ICD-10 code C61), lung cancers (ICD-10 codes C33-C34) and colorectal cancers (ICD-10 codes C18-C20).

Lincolnshire Summary:

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2018 shows a distinctive jump in cancer instances from 2017. The data shows a 6% increase on all cancers from the previous year in Lincolnshire compared to a less than 1% rise from 2016 to 2017. This is partially mirrored nationally (4% increase) but is still significantly above.
The bulk of the increase appears to be within prostate cancers which has a 22.6% increase from the previous year.
Incidence rates per 100,000 registered population has shown a decreasing trend nationally in recent years, but there is a 2% uptick in 2018. Lincolnshire has been traditionally below the national rates however Lincolnshire had a 5% uptick in 2018 which has put it above the national rates for the first time. Again the increase is predominantly due to prostate cancers.

Population growth

Actual Registrations population changes by CCG

Lincolnshire Raw List Size	2016/17 October 2016	2017/18 October 2017	2018/19 October 2018	2020/21 October 2020	1819 Increase	2021 Increase*
03T	246905	249330	251613		0.90%	
04D	234594	237376	235435		-0.80%	
04Q	132984	133468	134047		0.40%	
99D	165079	166540	168003		0.90%	
71E	779562	786714	789098	798803	0.30%	1.21%

*2020 not available retrospectively at time of writing. Merge of CCGs into NHS Lincolnshire CCG 71E

Population Predications

	0-14	15-64	65-74	75+	Total
2016	119000	454300	96400	74600	744300
2020	124510	488610	99043	86640	798803
2041	120500	453500	109900	140400	824300
2016 - 2020 Change	4.63%	7.55%	2.74%	16.14%	7.32%
2016 - 2041 Change	1.30%	-0.20%	14.00%	88.20%	10.70%

Source: Office for National Statistics

Based on ONS predicted population growth (2016)

For Lincolnshire in 2020 there has been a 7.5% increase in 15-64 and 16% increase in 75+ since 2016

The population of Lincolnshire in 2016 was 744300. This was predicted to rise to 799300 by 2030, and to 824300 by 2041. It is an aging population, with numbers of people aged 75 years and over predicted to increase by 88.2% by 2041%. These predictions need to be reviewed as we are already reaching the 2030 levels.

Current patient experience performance (NCPES)

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The most recent National Cancer Patient Experience Survey was carried out in 2019 and the results published in June 2020.

Locally, at Clinical Commissioning Group level, the overall patient experience scores are[10]:

Overall patient experience (scale 0 very poor – 10 very good)	2017	2018	2019
England	8.80	8.80	8.80
NHS Lincolnshire East CCG	8.75	8.70	8.70
NHS Lincolnshire West CCG	8.57	8.50	8.50
NHS South Lincolnshire CCG	8.70	8.80	8.60
NHS South West Lincolnshire CCG	8.72	8.60	8.70

The following seven questions are included in phase 1 of the Cancer Dashboard developed by Public Health England and NHS England:

[10] National cancer patient experience surveys 2018 and 2019. Latest figures available are derived from the 2019 survey which was conducted prior to the establishment of Lincolnshire CCG. Figures at CCG level are therefore for the 4 Lincolnshire CCGs which have since merged.

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	England		ULHT		LECCG		LWCCG		SLCCG		SWLCCG	
	2017	2019	2017	2019	2017	2019	2017	2019	2017	2019	2017	2019
Q61. Patient's average rating of care scored from very poor to very good	8.8	8.8	8.6	8.5	8.8	8.7	8.6	8.5	8.7	8.6	8.7	8.7
Q18. Patient definitely involved as much as they wanted in decisions about care and treatment	79%	81%	75%	76%	77%	77%	73%	73%	78%	82%	78%	84%
Q19. Patient given the name of a CNS who would support them through their treatment.	91%	92%	86%	86%	87%	88%	85%	87%	92%	91%	91%	87%
Q20. Patient found it very or quite easy to contact their CNS	86%	85%	85%	83%	87%	85%	83%	77%	87%	87%	88%	84%
Q39. Patient always felt they were treated with respect and dignity while in hospital	89%	88%	86%	86%	86%	87%	84%	90%	90%	93%	95%	81%
Q41. Hospital staff told patient who to contact if worried about condition or treatment after leaving hospital	94%	94%	95%	91%	96%	93%	94%	90%	94%	94%	97%	94%
Q55. General practice staff definitely did everything they could to support patient during treatment	60%	58%	59%	58%	55%	54%	66%	64%	56%	55%	68%	55%

Key	
2019 score better than 2017	
2019 the same as 2017	
2019 score worse than 2017	

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Cancer Quality of Life Survey

In September 2020 the new Quality of Life survey was introduced. The first reports are due to be published in late 2021 by NHS England

Impact of Coronavirus pandemic

The COVID 19 pandemic had a significant impact on the Lincolnshire Living with Cancer Programme. Having secured funding from Macmillan in December 2019 to deliver 'Integrated Right by You' (ie. the delivery arm of the programme) this was reduced in May 2020 due to drastic funding issues experienced by Macmillan. In addition, other cancer service recovery and restoration priorities impacted on LWC funding from East Midlands Cancer Alliance.

This significant funding reduction for the LWC programme (approximately £1.754m over 3 years) resulted in the need to re-plan the programme to deliver objectives within a reduced financial and resource envelope. Redeployment of staff, retirement and migration of team members to substantive roles in other parts of the Lincolnshire system exacerbated this. In addition, the impact of the pandemic on other parts of the system, most significantly the Voluntary and Community Sector (which became extremely vulnerable), further impacted on the capacity of the programme to deliver its objectives at the scale and pace originally planned.

In response to phase 2 and 3 guidance from NHS England, restore and recovery plans were drafted and presented to Cancer Board on 29th June 2020 and Living with Cancer Board on 9th July 2020. Both Boards signed off the plans and attached action plans. Restore and Recovery plans were delivered during 2020 and quarters 1 and 2 of 2021.

The Restore and Recovery plans proposed that due to funding and resource reductions on the programme, a full re-plan of the programme was necessary to deliver strategic and operational objectives.

The re-plan of programme retained the original approach, and re-emphasised tackling health inequalities and a focus on those people affected by cancer with the greatest need, long term condition prevention and management, utilising existing assets and collaborative whole system working within reduced financial and resource envelope.

Furthermore, the re-plan focussed on system integration of the programme by 2023. Programme input into the Lincolnshire Long Term Plan refresh 2020 – 2024 reflected this.

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Options for the delivery of the LWC Programme were considered by LWC Board in July 2020 and an option agreed. A bid for funding from the Macmillan Covid Response Fund to support the selected option was subsequently submitted and was successful.

The re-planned Living with Cancer programme commenced on 1st April 2021. Further funding has subsequently been secured from Macmillan Cancer Support, East Midlands Cancer Support, Health Education England and the Estates and Technology Transformation Fund to enhance the scale and pace of delivery of the programme

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Our achievements 2019 – 2021

In the two years that the LWC Strategy 2019 – 2021 was live, we made progress towards meeting our strategic objectives during a period of uncertainty during the Covid pandemic. As a result the delivery of the programme was re-planned and we have continued to lay down firm foundations for the delivery of the programme during 2021 – 2023 and onwards post 2023 as 'business as usual'.

The programme achievements to date are:

- Worked within a governance structure which allows decision making and reporting, and aligns with the wider cancer improvement governance structure (Cancer Board).
- Secured £1.07m 'Integrated Right by You' funding from Macmillan in December 2019.
- Maintained the programme through the Covid pandemic, developed and delivered Restore and Recovery plans.
- Following a reduction in funding due to the pandemic, re-planned the programme around 3 sub-programmes (Acute, Personalisation and Community Development Programmes) and cross-cutting work streams (Strategy, Governance, Engagement, Communications and Evaluation) and plans (Workforce Development, Digital and Sustainability plans)
- Secured funding from the Macmillan Covid Response Fund, East Midlands Cancer Alliance, Health Education England and Estates and Technology Transformation Fund to deliver the programme. Recruited 6 members of staff for 1.5 years. Identified further posts to enhance the delivery of the programme in 2021 – 2023 should funding become available.
- LWC Acute Facilitators (as were) continued to work in Lincolnshire's three hospitals on rolling out holistic needs assessments and treatment summaries to patients on our priority tumour pathways, which are breast, prostate and colorectal and additional pathways. HNAs continued to be completed throughout the Covid pandemic.
- LWC Community Facilitators (as were) continued work in all Neighbourhood Team localities and primary care to roll our cancer care reviews and access to health and wellbeing environments.
- LWC Community Facilitators (as were) developed a menu of options for GP practices to improve the quality of Cancer Care Reviews. Options included opportunity to achieve Macmillan Excellence in Cancer Care Award, Nurse Led CCR training, CCR protocol, resources for patients to remind them about CCRs, script for nurses when telephoning patients to arrange CCR (both developed with the Macmillan LWC Co-Production group. Project briefs for the Psychological and Emotional Support and Physical Activity health and wellbeing elements were developed.
- Working in partnership with the IAPTs service in the Mental Health Trust (LPFT) a pilot project was developed and started enabling CNSs to refer patients directly into the service following an HNA.

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- LWC Acute and Community Facilitators consolidated relationships across the system: in Acute, in Primary Care, in communities and in the voluntary sector.
- Delivered project to identify the best option for Remote Monitoring in breast, prostate and colorectal follow up pathways. Secured funding and purchased Somerset Remote Monitoring Module.
- Working with EMCA, achieved clinical sign off for PFUP in Breast. Participated in development of regional protocol Prostate PFUP.
- Collaborated with the Lincolnshire Personalisation Programme, to test delivery options for key Personalisation elements in Personalised care and support planning, Patient Activation, Social Prescribing models and Shared Decision Making.
- Completed Shared Decision Making project and delivered report and recommendations to implement in the context of the Living with Cancer Programme (workforce development and patient communications).
- The new Macmillan Information and Support Service opened at Lincoln County Hospital. The centre continued to support people throughout the pandemic by moving face to face support to virtual support either by telephone or by video call. The Lincoln team were the first team in the country to do this.
- Identified and secured funding to continue Macmillan GP support beyond the original 2 year period.
- Developed and delivered engagement plans for all our projects, and developed and delivered communications plans which raise the profile of our work and of cancer in Lincolnshire.
- Identified other projects and work streams which will enhance the programme if further funding becomes available (our 'wish list')
- Participated in the development of regional protocol and case for change for Psychological and Emotional support for people living with cancer.
- Collaborated with Active Lincolnshire and Lincoln City Foundation to scope and develop 'Fighting Fit' physical activity programme.
- Supported the Macmillan Living with Cancer Co-Production Group. Continued to support the group as it moved to a virtual group during the pandemic. Secured funding from Macmillan to continue the group or a further 18 months
- Completed our evaluation programme to measure the impact of the programme and delivered an evaluation report. We worked with Frontline Consultants to do this.
- Secured funding from Macmillan to continue to support four Cancer Care Coordinators (2 for Breast and 2 for Urology) for a further 2 years beyond the original funding period. Secured funding for two cancer Care Co-ordinators in the chemotherapy suite and two Cancer Care Co-ordinators in the lung pathway
- Planned and delivered the Lincolnshire Cancer Summit 2019 at the University of Lincoln.

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- Worked with the University of Lincoln to develop and build the 'Shared Lives: Cancer' website. This website is a global first, and aims to bring together academic research and lived experience to support further academic research and peer support via the sharing of lived experience by people living with cancer.
- The Lincolnshire Prehabilitation programme secured funding to expand their project to chemotherapy as well as radiotherapy patients, and across the county.
- Positioned ourselves to align with Lincolnshire Long Term Plan priorities by which we aim to sustain funding and momentum.
- Started preparatory work to develop sustainability plan which aims to integrate the LWC programme with Lincolnshire ICS in 2023.
- Placed people affected by cancer at the centre of everything we do, and remained true to our principles and values.
- Worked in a way which brings credibility to our programme, and are influential in the county. We have worked hard to forge relationships both between ourselves and other services and organisations, and to bring services together to work collaboratively.

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NHS Lincolnshire Sustainability and Transformation Partnership

Measuring our success 2019 - 2021

In 2017 we developed an outcomes framework for the LWC Strategy 2017 - 2019 (see page 41) by which can self-assess our success in addressing our strategic themes and meeting our aim and objectives. This framework remained relevant as the programme moved into the second strategy phase.

In the LWC Strategy 2019 – 2021 we applied metrics to this outcomes framework aligned to Lincolnshire Cancer Improvement Plan objectives and performance indicators. The Covid pandemic had a significant impact on the programme's capacity to meet these deliverables. This was reflected across the Lincolnshire system, and the England. NHS England subsequently amended their deliverables (which are set out in this strategy). The table shows the status of delivery on the original deliverables in March 2021.

Objective/deliverable	Metric	Status
Ensuring every patient has access to optimal clinical pathways, personalised treatment, needs assessment, care plan and effective follow up including health and wellbeing information advice and support.	By June 2019 LWC programme will adopt the LWC Strategy 2.	Achieved
	By April 2019 the STP will implement the follow up pathway for stable prostate cancer patients >2 years in primary care.	Not achieved
	By March 2020 the STP will introduce risk personalised follow up for patients with breast and prostate cancer.	Partially achieved
	By April 2021 the STP will work towards all patients receiving a full assessment of their needs an individual care plan and information and support for their wider health and wellbeing.	Partially achieved
Improved Patient Experience	The STP will work to improve the national patient experience survey results for 2019 rating their overall care >8.7.	Not achieved
	During 2019 the LWC programme will co-produce the programme with people living with cancer (these elements will be determined by the group).	Achieved
Key performance indicators	By April 2019 25% of patients diagnosed with breast and prostate cancer will have had a Holistic Needs Assessment (HNA) completed.	Not achieved
	By December 2019 60% of patients diagnosed with prostate cancer will have had an HNA and care plan completed.	Not achieved

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	By December 2019 60% of patients diagnosed with breast cancer will have had an HNA and care plan completed.	Partially achieved
	By December 2020 95% of patients diagnosed with breast and prostate cancer will have had an HNA and care plan completed.	Not achieved

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Outcomes Framework 2019 - 2021

AIM	To develop person centred place based support for people living with and beyond cancer, their carers and significant others in Lincolnshire											Principles and values						
OBJECTIVES	End to end integrated support pathways across the statutory and voluntary sectors which will improve outcomes and support people Living With and Beyond Cancer are developed	People Living With and Beyond Cancer are active participants in supported self-management.	People delivering health and social care, work in partnership to facilitate supported self-management	By 2021 all people Living With and Beyond Cancer will have access to the Recovery Package and stratified follow up pathways of care and support.	A tested and flexible service delivery model is operational in Lincolnshire	A partnership across all stakeholders is established to transform cancer care into a whole systems approach which becomes everyday business.	The programme is co-designed with patients, the public and stakeholders.	The programme is fully evaluated to measure the impact and outcomes on the experience of patients, carers and significant others, and the workforce, and recommendations for future evaluation and measurement of the programme are delivered	There are the right people in the right place with the right skills to provide timely support for people Living With and Beyond Cancer across the county.	The programme aligns and integrates with other strategic, organisational and operational developments locally.	People Living With and Beyond Cancer experience seamless and co-ordinated pathways of support.	Everything we do places the person at the centre.	The programme is developed using a whole person, whole pathway, whole system approach.	The programme fully aligns with existing and new systems.	The programme takes account of 'place', in that it promotes and develops services which support people in the place of the	The programme promotes Self Care principles	The programme adopts an Asset Based Community Development approach	The programme is delivered embracing innovation
TIMESCALE	31/05/2021	31/05/2021	31/05/2021	31/05/2021	31/05/2021	31/05/2021	31/05/2021	31/05/2020	31/05/2021	31/05/2021	31/05/2021							
KEY WORKSTREAMS	Communication and conversations Tackling inequity Access to information, advice and support Information governance Integration Service development Pathways Workforce																	
OUTCOMES (MACMILLAN PRIORITIES)	Everyone with cancer knows they can turn to Macmillan and how we can help from the moment they are diagnosed Everyone with cancer has a conversation about all their needs and concerns and gets the right support to find their best way through Everyone has their vital needs met through high quality services Everyone with treatable but not curable cancer is supported to live life as fully as they can More people are inspired to give to Macmillan so we can continue to be there for people when they need us most We improve the key processes which support Macmillan to do their work as effectively as possible																	
METRICS	STP Cancer Improvement Plan metrics 2019 EMCA metrics (to be adopted) Improvement in patient experience (National Patient Experience Survey)																	

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The programme worked towards meeting the outcomes framework in the following ways:

1.	We will develop end to end integrated support pathways across the statutory and voluntary sectors which will improve outcomes and support people living with cancer.	• LWC Acute Facilitators (as were) continued to work in Lincolnshire's three hospitals on rolling out holistic needs assessments and treatment summaries to patients on our priority tumour pathways, which are breast, prostate and colorectal and additional pathways. HNAs continued to be completed throughout the Covid pandemic. • LWC Community Facilitators (as were) continued work in all Neighbourhood Team localities and primary care to roll our cancer care reviews and access to health and wellbeing environments. • LWC Community Facilitators (as were) developed a menu of options for GP practices to improve the quality of Cancer Care Reviews. Options included opportunity to achieve Macmillan Excellence in Cancer Care Award, Nurse Led CCR training, CCR protocol, resources for patients to remind them about CCRs, script for nurses when telephoning patients to arrange CCR (both developed with the Macmillan LWC Co-Production group. Project briefs for the Psychological and Emotional Support and Physical Activity health and wellbeing elements were developed. • Working in partnership with the IAPTs service in the Mental Health Trust (LPFT) a pilot project was developed and started enabling CNSs to refer patients directly into the service following an HNA. • LWC Acute and Community Facilitators consolidated relationships across the system: in Acute, in Primary Care, in communities and in the voluntary sector.

2.	People living with cancer are active participants in supported self-management.	• Collaborated with the Lincolnshire Personalisation Programme, to test delivery options for key Personalisation elements in Personalised care and support planning, Patient Activation, Social Prescribing models and Shared Decision Making. • Completed Shared Decision Making project and delivered report and recommendations to implement in the context of the Living with Cancer Programme (workforce development and patient communications). • Participated in the development of regional protocol and case for change for Psychological and Emotional support for people living with cancer. • Working in partnership with the IAPTs service in the Mental Health Trust (LPFT) a pilot project was developed and started enabling CNSs to refer patients directly into the service following an HNA. • Collaborated with Active Lincolnshire and Lincoln City Foundation to scope and develop 'Fighting Fit' physical activity programme.
3.	People delivering health and social care, work in partnership to facilitate supported self- management.	• LWC Acute Facilitators (as were) continued to work in Lincolnshire's three hospitals on rolling out holistic needs assessments and treatment summaries to patients on our priority tumour pathways, which are breast, prostate and colorectal and additional pathways. HNAs continued to be completed throughout the Covid pandemic. • LWC Community Facilitators (as were) continued work in all Neighbourhood Team localities and primary care to roll our cancer care reviews and access to health and wellbeing environments.

		• Collaborated with the Lincolnshire Personalisation Programme, to test delivery options for key Personalisation elements in Personalised care and support planning, Patient Activation, Social Prescribing models and Shared Decision Making. • Working in partnership with the IAPTs service in the Mental Health Trust (LPFT) a pilot project was developed and started enabling CNSs to refer patients directly into the service following an HNA. • Collaborated with Active Lincolnshire and Lincoln City Foundation to scope and develop 'Fighting Fit' physical activity programme. • Planned and delivered the Lincolnshire Cancer Summit 2019 at the University of Lincoln. • Worked with the University of Lincoln to develop and build the 'Shared Lives: Cancer' website. This website is a global first, and aims to bring together academic research and lived experience to support further academic research and peer support via the sharing of lived experience by people living with cancer. • Worked in a way which brings credibility to our programme, and are influential in the county. We have worked hard to forge relationships both between ourselves and other services and organisations, and to bring services together to work collaboratively.
4.	We will support roll out and access to the Recovery Package and personalised follow up pathways of care and support for all people living with cancer.	• Delivered project to identify the best option for Remote Monitoring in breast, prostate and colorectal follow up pathways. Secured funding and purchased Somerset Remote Monitoring Module.

		• Working with EMCA, achieved clinical sign off for PFUP in Breast. Participated in development of regional protocol Prostate PFUP.
5.	A tested and flexible service delivery model is operational in Lincolnshire.	• The new Macmillan Information and Support Service opened at Lincoln County Hospital. The centre continued to support people throughout the pandemic by moving face to face support to virtual support either by telephone or by video call. The Lincoln team were the first team in the country to do this. • Collaborated with Active Lincolnshire and Lincoln City Foundation to scope and develop 'Fighting Fit' physical activity programme. • Secured £1.07m 'Integrated Right by You' funding from Macmillan in December 2019. • Following a reduction in funding due to the pandemic, re-planned the programme around 3 sub-programmes (Acute, Personalisation and Community Development Programmes) and cross-cutting work streams (Strategy, Governance, Engagement, Communications and Evaluation) and plans (Workforce Development, Digital and Sustainability plans) • Secured funding from the Macmillan Covid Response Fund, East Midlands Cancer Alliance, Health Education England and Estates and Technology Transformation Fund to deliver the programme. Recruited 6 members of staff for 1.5 years. Identified further posts to enhance the delivery of the programme in 2021 – 2023 should funding become available.
6.	A partnership across all stakeholders is established to transform cancer care into a whole systems approach which becomes	• Positioned ourselves to align with Lincolnshire Long Term Plan priorities by which we aim to sustain funding

	everyday business.	and momentum. • Started preparatory work to develop sustainability plan which aims to integrate the LWC programme with Lincolnshire ICS in 2023.
7.	The programme is co-designed with patients, the public and stakeholders.	• Placed people affected by cancer at the centre of everything we do, and remained true to our principles and values. • Supported the Macmillan Living with Cancer Co-Production Group. Continued to support the group as it moved to a virtual group during the pandemic. Secured funding from Macmillan to continue the group or a further 18 months • Developed and delivered engagement plans for all our projects, and developed and delivered communications plans which raise the profile of our work and of cancer in Lincolnshire.
8.	The programme is fully evaluated to measure the impact and outcomes on the experience of patients, carers and significant others, and the workforce, and recommendations for future evaluation and measurement of the programme are delivered.	• Completed our evaluation programme to measure the impact of the programme and delivered an evaluation report. We worked with Frontline Consultants to do this.
9.	There are the right people in the right place with the right skills to provide timely support for people living with cancer across the county.	• Identified and secured funding to continue Macmillan GP support beyond the original 2 year period. • LWC Acute Facilitators (as were) continued to work in Lincolnshire's three hospitals on rolling out holistic needs assessments and treatment summaries to patients on our priority tumour pathways, which are breast, prostate and colorectal and additional pathways. HNAs continued to be completed throughout the Covid pandemic. • LWC Community Facilitators (as were) continued work in all Neighbourhood

		Team localities and primary care to roll our cancer care reviews and access to health and wellbeing environments. • LWC Community Facilitators (as were) developed a menu of options for GP practices to improve the quality of Cancer Care Reviews. Options included opportunity to achieve Macmillan Excellence in Cancer Care Award, Nurse Led CCR training, CCR protocol, resources for patients to remind them about CCRs, script for nurses when telephoning patients to arrange CCR (both developed with the Macmillan LWC Co-Production group. Project briefs for the Psychological and Emotional Support and Physical Activity health and wellbeing elements were developed. • Working in partnership with the IAPTs service in the Mental Health Trust (LPFT) a pilot project was developed and started enabling CNSs to refer patients directly into the service following an HNA. • Collaborated with Active Lincolnshire and Lincoln City Foundation to scope and develop 'Fighting Fit' physical activity programme • Secured funding from Macmillan to continue to support four Cancer Care Coordinators (2 for Breast and 2 for Urology) for a further 2 years beyond the original funding period. Secured funding for two cancer Care Co-ordinators in the chemotherapy suite and two Cancer Care Co-ordinators in the lung pathway. • The Lincolnshire Prehabilitation programme secured funding to expand their project to chemotherapy as well as radiotherapy patients, and across the county.

10	The programme aligns and integrates with other strategic, organisational and operational developments locally.	• Worked within a governance structure which allows decision making and reporting, and aligns with the wider cancer improvement governance structure (Cancer Board). • Collaborated with the Lincolnshire Personalisation Programme, to test delivery options for key Personalisation elements in Personalised care and support planning, Patient Activation, Social Prescribing models and Shared Decision Making. • Completed Shared Decision Making project and delivered report and recommendations to implement in the context of the Living with Cancer Programme (workforce development and patient communications). • Positioned ourselves to align with Lincolnshire Long Term Plan priorities by which we aim to sustain funding and momentum. • Started preparatory work to develop sustainability plan which aims to integrate the LWC programme with Lincolnshire ICS in 2023.

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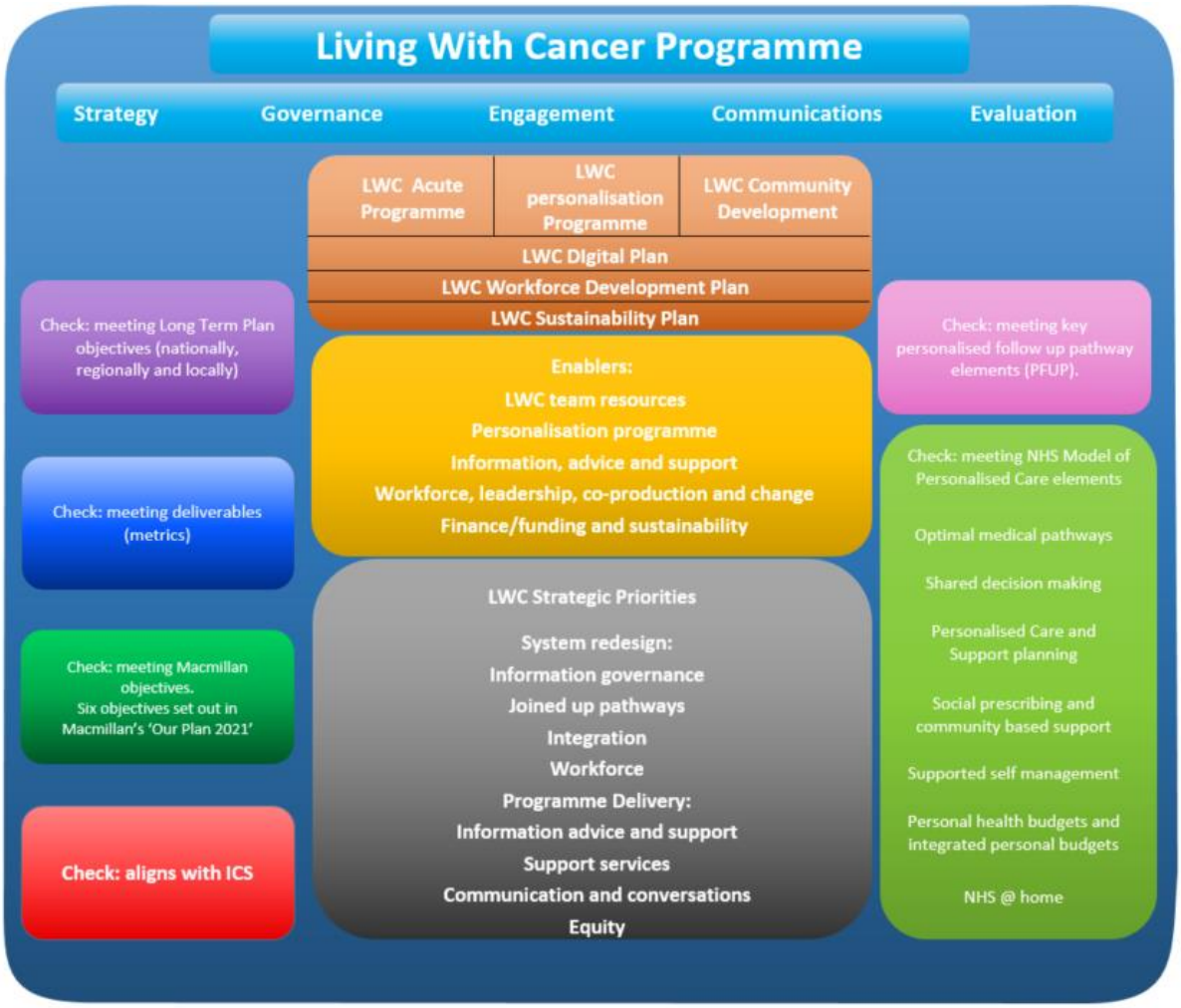
Appendix 2: LWC programme 2021 – 2023 Programme framework, Outcomes Framework and Strategic Action Plan 2021 – 2023

LWC Programme Framework 2021 – 2023



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Outcomes Framework 2021 – 2023

AIM	To develop person centred place based support for people living with and beyond cancer, their carers and significant others in Lincolnshire											Principles and values						
OBJECTIVES	End to end integrated support pathways across the statutory and voluntary sectors which will improve outcomes and support people Living with Cancer are developed	People Living with Cancer are active participants in supported self-management.	People delivering health and social care, work in partnership to facilitate supported self-management	By 2023 all people living with cancer will have access to the personalised care and personalised follow up pathways of care and support.	A tested and flexible service delivery model is operational in Lincolnshire	A partnership across all stakeholders is established to transform cancer care into a whole systems approach which becomes everyday business.	The programme is co-designed with patients, the public and stakeholders.	The programme is fully evaluated to measure the impact and outcomes on the experience of patients, carers and significant others, and the workforce, and recommendations for future evaluation and measurement of the programme are delivered	There are the right people in the right place with the right skills to provide timely support for people Living with Cancer across the county.	The programme aligns and integrates with other strategic, organisational and operational developments locally.	People Living with Cancer experience seamless and co-ordinated pathways of support.	Everything we do places the person at the centre.	The programme is developed using a whole person, whole pathway, whole system approach.	The programme fully aligns with existing and new systems.	The programme takes account of 'place', in that it promotes and develops services which support people in the place of their	The programme promotes Self Care principles	The programme adopts an Asset Based Community Development approach	The programme is delivered embracing innovation
TIMESCALE	31/03/2023	31/03/2023	31/03/2023	31/03/2023	31/03/2023	31/03/2023	31/03/2023	31/03/2023	31/03/2023	31/03/2023	31/03/2023							
KEY WORKSTREAMS	Communication and conversations Tackling inequity Access to information, advice and support Information governance Integration Service development Pathways Workforce																	
OUTCOMES (MACMILLAN PRIORITIES)	We want everyone with cancer to know that they can turn to Macmillan and how we can help from the moment they are diagnosed We want everyone to have a conversation about all their needs and concerns, and get the support that's right for them We want everyone to have their vital needs met by high quality services More people are inspired to give to Macmillan so we can continue to be there for people when they need us most We want to improve the key processes which support Macmillan to do its work as efficiently and effectively as possible We will reflect and represent the communities we serve in everything we do to support everyone living with cancer																	
METRICS	Personalised Follow up Pathways Four LWC interventions - HNA, TS, CCR & Health & Wellbeing Improvement in patient experience (QoL and National Patient Experience Survey)																	

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Strategic Action Plan 2021 – 2023

Living with Cancer Programme Strategic Action Plan 2021 - 2023						
LWC Objective	**What good looks like**	**Where are we now?**	**What needs to change?**	**What actions do we take?**	**By when?**	**What measures our success?**
1	We will develop end to end integrated support pathways across the statutory and voluntary sectors which will improve outcomes and support people living with and beyond cancer.	Personalised follow up pathways in Breast and Prostate adopted but not operationalized. PFUP protocol in Colorectal developed by EMCA.. EMCA to develop PFUP in Endometrial, Lymphoma and Skin pathways.. LWC Acute, Personalisation and Community Development programmes underway	Operationalise breast and Prostate PFUP.	Develop personalised follow up pathways for breast, prostate, colorectal, endometrial and two other cancers by 2022. Work with the East Midlands Cancer Alliance to make sure that clinically agreed personalised follow up pathways are implemented in Lincolnshire, in a way that is appropriate to the needs of Lincolnshire residents.	March 2022.	National, Regional and Local Metrics and KPIs to be defined - ICS & System LTP in development.

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			Adopt Colorectal PFUP. Adopt Endometrial, Lymphoma and Skin PFUP.	Use this learning to develop personalised follow up pathways for other cancers.		
			Full roll out of Acute, Personalisation and Community Development Programmes, consistent framework with local variance to take account of population needs. Deliver Digital and Workforce Plans	Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings.	March 2023.	
				Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks.		

				Implement all four living with cancer interventions: holistic needs assessments, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to take account of population needs.		
2	People living with and beyond cancer are active participants in supported self- management.	Lincolnshire Personalisation programme developing methods of supporting active self-management. Data collection to evidence underdeveloped. Social prescribing services supported by Lincolnshire Personalisation Programme	Access to reliable information about local support services.	Make sure that people have access to reliable information and advice about local support services in a format that meets their needs, including digital solutions.	March 2023.	

		and delivered via PCNs. On-going funding fragile. PCSP supported by Lincolnshire Digital Programme.	Access to full range of services that support active self-management.	Make sure that people can access a full range of services that support active self-management by developing and implementing a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings.		
			Proactive identification of potential needs.	Make sure that people's needs are identified in a proactive way by implementing holistic needs assessments and personalised care plans		

			Improved access to all health and wellbeing elements.	Use existing assets to make sure those different levels of need in health and wellbeing are catered for, starting at self-care, all the way through to professionally led support. If there are gaps, we will explore ways of filling those gaps.		
3	People delivering health and social care, work in partnership to facilitate supported self-management.	Services don't work in an integrated way, and the transition between services, and different stages of a patient's experience are disjointed. Organisations do not communicate very well between themselves. NWTs developed, some variance in levels of maturity. PCN Model adopted in Lincolnshire.	Full integration of LWC programme with NWTs and PCNs.	Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks.	March 2023.	
			Improved awareness of LWC programme, LWC interventions and services/support available in primary care/communities. Improved communication.	Align our work with the Lincolnshire Personalisation Programme.		

			Improve knowledge of supporting people LWC and Community Based Support in Primary Care, VCS, SP and other support services. Improve knowledge of Community Based Support with cancer specific workforces in Acute.	Identify different workforces that support people living with cancer, and using our People Plan, make sure they have the skills, knowledge and confidence to support people living with cancer.		
4	Support the roll out and access to personalised care and personalised follow up pathways of care and support for all people living with and beyond cancer.	Acute programme prioritising roll out of HNAs and TS in breast, prostate and colorectal pathways. Working with CNS teams on other pathways and points on pathways. Personalisation Programme developing Triage/Navigate/Refer/Record model. PFUP priorities breast, prostate, colorectal, endometrial, lymphoma and skin. Community Development Programme working with all NWTs and PCNs in county, focussing on CCRs and access to Health and Wellbeing environments. priority H&WB elements - psychological and emotional Support, physical activity,	Full roll out of Acute, Personalisation and Community Development Programmes, consistent framework with local variance to take account of population needs. Deliver Digital and Workforce Plans	Work with the East Midlands Cancer Alliance to make sure that clinically agreed personalised follow up pathways are implemented in Lincolnshire, in a way that is appropriate to the needs of Lincolnshire residents. Develop personalised follow up pathways for breast, prostate, colorectal, endometrial and two other cancers by 2022.	March 2022.	

		body image. Other H&WB elements to follow. Digital and workforce plans developed.		Use this learning to develop personalised follow up pathways for other cancers.		
				Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings.	March 2023.	
				Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks.		

				Implement all four living with cancer interventions: holistic needs assessments, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to take account of population needs.		
5	A tested and flexible service delivery model is operational in Lincolnshire.	No consistent delivery model.	Develop consistent model of Triage/Navigate/Refer/Record which can be delivered by different staff groups at different points on pathways.	Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings.	March 2023.	
				Work with existing service delivery providers to come up with innovative delivery solutions for example the Fighting Fit Programme.		

6	A partnership across all stakeholders is established to transform cancer care into a whole systems approach which becomes everyday business.	LWC programme included as part of ICS system transformation.	LWC programme integrated with ICS with sustainable funding. Alignment with delivery of support for other long term conditions to maximise personalised care and support options.	Integrate the Living with Cancer programme into the Lincolnshire Integrated Care System by 2023. Work with other long term condition programmes and the Lincolnshire Personalisation Programme to come up with a consistent model of support which can be used across different condition pathways, with flexibility to support the particular needs of people living with cancer.	March 2023.	

7	The programme is co-designed with patients, the public and stakeholders.	Patient engagement carried out for Strategy 1 development. Funding secured for two LWC Co-production Groups - one established and one being established on east coast. EBE project approved by cancer board. Communications and Engagement plan in development.	Support Co-production Groups and utilise results. Establish Cancer Patient Panel. Implement Cancer Communication Plan, and programme/project engagement plans.	Continue to support the Macmillan Living with Cancer Co-production Group and make sure that they are able to co-produce parts of the programme that are meaningful to them.	March 2023.	
				Support the establishment of new LWC Co-Production groups in different parts of the county, and with different cohorts of patients.		
				Develop a refreshed Living with Cancer communications and engagement plan so that people can be involved in the programme.		
				Work with the ULHT Expert by Experience Programme and patient Experience team to establish a Cancer Patient Panel.		

8	The programme is fully evaluated to measure the impact and outcomes on the experience of patients, carers and significant others, and the workforce, and recommendations for future evaluation and measurement of the programme are delivered.	Formative evaluation and theory of change completed.	Implement recommendations from evaluation programme. Secure funding/resources to complete summative evaluation of programme. Ensure recommendations from national patient experience surveys implemented.	Implement the recommendations of and build on the Living with Cancer Evaluation Programme carried out in 2020	March 2023.	
				Carry out a further evaluation at the end of the external funding in 2023.		
				Ensure that recommendations from the Quality of Life and National Cancer Patients' Experience Surveys are carried out.		
9	There are the right people in the right place with the right skills to provide timely support for people living with and beyond cancer across the county.	Acute workforce across three trust sites. Macmillan nurses for end of life care. NWTs and PCNs established. Workforce to support psychological and emotional support patchy.	Full integration of LWC programme with NWTs and PCNs.	Develop a Living with Cancer People Plan and make sure it aligns with the Lincolnshire ICS People Plan.	March 2023.	

		Volunteer project exists but not in all areas. Funding secured for Macmillan GPs. Social prescribing workforce attached to PCNs. VCS in recovery after Covid pandemic.	Improved awareness of LWC programme, LWC interventions and services/support available in primary care/communities. Improved communication.	Make the most of our existing workforces, identify their needs, and make sure they have the skills, knowledge and confidence to support people living with cancer.		
			Improve knowledge of supporting people LWC and Community Based Support in Primary Care, VCS, SP and other support services.			
			Improve knowledge of Community Based Support with cancer specific workforces in Acute.	Support the creation and longevity of new roles if necessary.		
10	The programme aligns and integrates with other strategic, organisational and operational developments locally.	LWC programme included as part of ICS system transformation. LWC programme strategically aligned with national, regional and local strategies and policies.	Full integration of LWC programme with ICS.	Work with other long term condition programmes and the Lincolnshire Personalisation Programme to develop a consistent model of support which can be delivered across the system, but is flexible enough to support people living with cancer in different communities.	March 2023.	

				Integrate the Living with Cancer programme into the Lincolnshire Integrated Care System by 2023.		
				Work closely with Macmillan Cancer Support, East Midlands Cancer Alliance and NHS England to make sure we meet local, regional and national objectives.		
				Make the most of our digital assets, and make sure everything we do aligns with the Lincolnshire ICS digital plan.		
11	People living with and beyond cancer experience seamless and co-ordinated pathways of support.	Personalised follow up pathways in Breast and Prostate adopted but not operationalized. PFUP protocol in Colorectal developed by EMCA.. EMCA to develop PFUP in Endometrial, Lymphoma and Skin pathways.. LWC Acute,	Operationalise breast and Prostate PFUP.	Develop personalised follow up pathways for breast, prostate, colorectal, endometrial and two other cancers by 2022.	March 2022.	

		Personalisation and Community Development programmes underway	Adopt Colorectal PFUP. Adopt Endometrial, Lymphoma and Skin PFUP.	Work with the East Midlands Cancer Alliance to make sure that clinically agreed personalised follow up pathways are implemented in Lincolnshire, in a way that is appropriate to the needs of Lincolnshire residents.		
				Use this learning to develop personalised follow up pathways for other cancers.		
			Full roll out of Acute, Personalisation and Community Development Programmes, consistent framework with local variance to take account of population needs. Deliver Digital and Workforce Plans	Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings.	March 2023.	

				Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks.		
				Implement all four living with cancer interventions: holistic needs assessments, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to take account of population needs.		

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				Integrate the Living with Cancer programme into the Lincolnshire Integrated Care System by 2023.		

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Appendix 3: Annie's Case Study

Annie Theed is a Cancer Care Co-ordinator in the breast team at Boston Pilgrim Hospital. Annie supports patients who are undergoing treatment for breast cancer. What follows, in Annie's own words, is an example of the difference personalised care can make to a patient's life.

Background

- Patient 53 years old.
- Marital status – Single
- Mother & grandmother.
- First diagnosed with breast cancer in 2007.
- Recurrence 2017.
- Under the care of the Oncologist.
- Had never received a HNA as was referred from breast prior to HNAs being routinely carried using the Somerset Cancer Register software and although she was seen in a diagnostic clinic in June 2019 she was discharged from our care after this appointment and was continuing her care under Oncology.

I was emailed by the cancer treatment care co-ordinator requesting I contact the breast cancer patient to offer a HNA as they were due to start palliative chemotherapy in a couple of weeks.

I contacted the patient on the 19th June 2020 to offer a HNA.

It soon became apparent that the patient required some help – she openly admitted she was feeling very low and it was generally down to her living conditions.

The patient was living in shared accommodation where she was sharing the kitchen and bathroom facilities with the other tenants.

Her room was on the ground floor with the window facing a very busy road – she was inclined to stay in her room due to self–isolating, and because there were quite a few pedestrians who would walk pass looking into her room, she tended to keep her curtains closed at all times.

The patient told me she was on the council housing list but was only on the bottom banding of the list.

I urged the patient to contact the council to explain to them about her medical needs.

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The patient agreed to do this. I also suggested to the patient that I could refer her case to the **Neighbourhood Hub** for them to investigate and to our counsellor affiliated with the Boston Breast unit. Patient agreed to both.

I placed the referral to the Neighbourhood Hub on the 19/06/2020, and they contacted me later the same day to update me.

They had discovered that the patient was on the bottom housing banding due to historical rent arrears that amounted to roughly £2500. Due to this she was unlikely to move up a band and was forbidden from holding a tenancy with Longhurst Housing Partnership (LHP) until the arrears were paid in full.

The patient was in not in a financial situation where she could afford to repay the arrears.

The Neighbourhood Hub had managed to get a verbal agreement that LHP would consider her application if she contacted them to discuss a 'repayment plan' on the arrears.

The Neighbourhood Hub also gave me the contact details of several other housing associations that operate in this area. I was not aware that there was so many.

I contacted the patient again and relayed the information from the Neighbourhood Hub. The patient, in my opinion sounded very resigned and despondent to my queries but once I told her of the possibility of a repayment plan – patient agreed to phone LHP immediately to discuss this.

The patient explained to me that the arrears had occurred in 2000-2001 when she had travelled to Turkey to get married and her new husband had initially refused to let her return to the UK – prior to this she had always kept up to date with her rent payments.

The patient was no longer married to this man.

Later that same day I received a phone call from the patient who sounded very distressed. She had contacted LHP who were adamant that all arrears must be paid in full prior to commencing a new tenancy agreement.

I tried my best to calm the patient and we agreed that I would contact her in a few days. Patient gave me verbal consent to discuss her case to any housing department that may be able to help her.

From the list I was given from the Neighbourhood Hub of other housing associations in the Boston area– I began contacting them personally to enquire about the criteria they have on people having a tenancy with them.

The first one I contacted was Housing 21 and I spoke to a gentleman there who stated that due to the current pandemic they actually had a flat that was ready to move into. He explained to me about

the criteria for a person to have a tenancy with themselves and it soon became apparent to me that 2 areas would be a stumbling block;

- A person had to be free of rent arrears of over £500 from any other housing association and that there was a plan in place to repay the remaining £500.
- A person had to be 55 years and older to hold a tenancy with themselves.

I felt like I had very quickly forged a good relationship with the Housing 21 gentleman and I briefly explained the patient's situation and although very sympathetic he felt there was very little that Housing 21 could do to help the patient.

Undeterred I asked the Housing 21 gentleman if it would be possible to appeal to the Housing 21 board to see if they would allow and consider an application from the patient, he agreed to plead our case for this.

I then began to gather supportive information to present to the board.

I was already aware that our Breast Cancer Counsellor had written a letter for the patient to present to the council which I believe would also be good evidence to submit to Housing 21 along with this I decided to write a letter as well.

The Housing 21 contact submitted both letters as well as his own brief summary of the situation and then it was a case of waiting. It took 5 whole days to get a decision – the Housing 21 board had agreed that the patient could have a property with them under a special tenancy agreement of 1 year (which meant that if she fell in arrears it would be easier for them to get the property back), after that year she would be able to be placed on a standard tenancy.

On signing the tenancy agreement the patient would have to pay 1 month's rent in advance amounting to around £444.

The patient was unable to work and was in receipt of social care benefits – I placed a referral to St. Barnabas welfare team in the hopes that the patient would be able to apply for a Macmillan grant.

She was successful and used some of this towards the first month's rent.

I then looked at local charities that could possibly help and after talking to our Living with & Beyond Cancer Project Manager who mentioned the Lions club. I decided to try them first.

After a brief explanation of why I was phoning them the Boston Lions club stated they would make some phone calls and hopefully they would be able to carpet the whole flat for free – they were successful with this and within 1 week of the patient being allocated the flat all rooms had either brand new carpets or lino.

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The patient did not require a cooker or washing machine as her flat had a cooker installed and the complex where her flat was had a laundry room.

Her 2 sons had also been buoyed by their mother getting her own place that they had sourced appliances for her and were taking time off work to help her move.

The patient signed her tenancy agreement on the 28th July 2020 and moved in on the 29th July 2020.

I contacted her on the 31/07/2020 as a courtesy call to see how she was and it was a very different patient on the other end – she was making plans to have her grandchildren stay over, she had kept all her curtains open and marvelled at how quiet it was.

The flat was situated a 5 minute walk away from her son's home and she planned to take this trip regularly.

She had made a friend with a lady who worked at the complex and they had quickly bonded over the fact they had both taken oral chemotherapy.

I am proud of the work I have undertaken to help this patient but I think this case especially highlights how different personnel within ULHT and outside agencies have all worked well together with clear communication, requests and information to help a patient.

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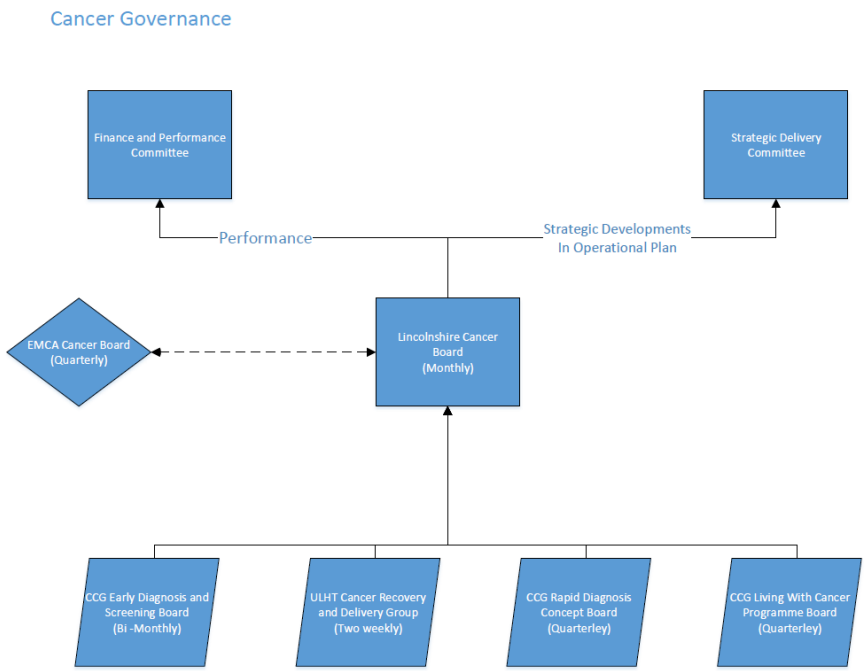
Appendix 4: LWC Governance Structure



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