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NHS
Lincolnshire
Integrated Care Board

Living with Cancer Strategy for Lincolnshire

2023 – 2025 with a forward view to 2028

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Table of contents

Executive Summary.....	4
Introduction.....	6
Our principles and values	8
Our vision 2023 - 2025.....	9
Making our vision a reality	13
How will we measure our success?	26
The future: a forward view to 2028.....	27
Appendix 1: Strategic alignment	28
Appendix 2: Patient, public and staff engagement 2023	29
Appendix 3: Governance of programme, action plan 2023 – 2025 and progress reporting. ...	30
Appendix 4: Key Performance Indicators 2023 – 2024, Living with Cancer Outcomes Framework.	32
Appendix 5: Lincolnshire Living with Cancer achievements 2021 – 2023.....	33
Appendix 6: Case studies	35

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 2040¹. 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 1970s². In Lincolnshire alone, with our ageing population and with these improvements in diagnosis, treatment and aftercare there are currently over 35,000³ people living with cancer, and this is expected to rise to 45400 by 2030.

People living with cancer in the county have told us that there are challenges to living well after a cancer diagnosis. These challenges fall into eight broad themes. These are:

- Information governance – your information.
- Joined up pathways – cancer pathways are often fragmented.
- Integrated services – sometimes services don't work together very well.
- Workforce – a workforce under pressure, and there are gaps.
- Conversations and communications – between services and between staff and patients.
- Information, advice and support – people don't know where to go to find out about this.
- Support services – people don't know about them; coverage is patchy and there are gaps.
- Inequity – your life circumstances can have an impact on your treatment, care and support.

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

Our aim:

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

¹ Macmillan Cancer Support 2018

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

³ 35,000 Cancer Register figures submitted in the QOF March 2023 return.

Our objectives are that by September 2025, 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.

Our approach

We are creating a better and sustainable future for supporting people LWC, involving and integrating all relevant parts of the health and social care system, using the assets we already have, supporting people in the place they would like and in the way they would like, and placing people at the centre of everything we do.

Introduction

There are currently 2.5 million people in the UK living with cancer; this is expected to rise to 5.3 million by 2040⁴. 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 1970s⁵.

In Lincolnshire alone, with our ageing population and with these improvements in diagnosis, treatment, and aftercare there are currently 35,000⁶ people living with cancer. This has risen from just over 32,000 in 2021 and is predicted to rise to 45400 by 2030.

The Lincolnshire Living with Cancer Strategy 2023 – 2025 is our 4th Strategy and sets out our approach and plans for the next 2 years with a forward view to 2028. It builds on the work carried out over the last seven years which was set out in the Living with Cancer Strategies 2017 – 2019, 2019 – 2021 and 2021 - 2023. The delivery of the programme during 2021 – 2023 saw the changes we have made become tangible and measurable and we have been able to demonstrate the impact of our work.

The legal framework and arrangement of how health and care services are delivered in Lincolnshire has undergone a substantial shift. On 1st July 2022 NHS Lincolnshire Integrated Care Board was established resulting in a much closer relationship between the statutory and voluntary sectors in the county and an ambition to have a different relationship with our residents. There is now an emphasis on prevention and proactive care, population health-based systems, tackling health inequalities and personalised care. This has been a positive move for the longevity of our programme and validated our approach.

Our approach put simply is ***'we are creating a better and sustainable future for supporting people LWC, involving and integrating all relevant parts of the health and social care system, using the assets we already have, supporting people in the place they would like and in the way they would like, and placing people at the centre of everything we do.'***

⁴ Macmillan Cancer Support 2018

⁵ Cancer: Then and Now. Diagnosis, treatment and aftercare from 1970 – 2016. Macmillan Cancer Support August 2016

⁶ 35,000 Cancer Register figures submitted in the QOF March 2023 return.

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In October 2022, eight Living with Cancer roles secured recurrent funding from Lincolnshire ICB and our Acute Trust, ULHT. We are working towards securing recurrent funding for our remaining four roles. This means that we will be able to continue our programme for people living with cancer, and we are working with other teams and programmes to understand if our working models can be used to support people with cancer and co-morbidities and other long-term conditions.

The commitment to place people at the centre of everything we do remains. We carried out our last major engagement programme to understand people's experiences in 2017. For this strategy it was time to carry out another engagement programme. During February to April of this year 356 people living with cancer and 43 staff members gave their time to respond to our survey, talk to the Lincolnshire ICB Engagement Team and attend a workshop. This strategy is informed by their stories, comments, and the changes they have told us they would like to see.

Elements of our programme have been co-produced since 2019 and we owe a debt of gratitude to our two Cancer Co-production Groups and Cancer Expert Reference Group who have given their time month after month to work with us, using their own experiences in a positive way to help current and future cancer patients, their carers, and significant others.

The Living with Cancer Programme could not have achieved everything that it has without the commitment and dedication of its amazing team, past and present, and unfailing support from our managers and senior and executive teams. It is fitting therefore that their efforts were recognised last year when the programme was awarded a Macmillan Excellence Award in the Integration category.

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.

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.

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.
- 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 building

Our vision 2023 – 2025

People living with cancer in Lincolnshire have told us that there are challenges to living well after a cancer diagnosis. In addition, our colleagues across Lincolnshire ICS have told us about the challenges that they, and the people they support and care for face. These challenges exist at different points on people’s cancer pathways and have helped us define our strategic priorities. They are:



Information governance – people get 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 make sure that people don’t have to travel back to hospital needlessly. We’re going to 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. People have told us that sometimes organisations don’t communicate very well between themselves either.

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Workforce – we’re going to make sure that we support our workforces during this programme. We are going to look at ways in which people living with cancer can be supported closer to where they live and 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 better.

Information, advice and support – many people have told 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. We are going to enhance the support that people can get in the hospital, at their pharmacy, in primary care, at work, in their community and at home.

Support services – we know that there are existing support services right across Lincolnshire. So, we’re going to look at ways in which we can use these more, make them stronger and help new services start to help fill the gaps. People have told us that the consequences of treatment, fatigue, and the impact on their mental health concerns them most. They have also said that they would like to see more support services for friends, family and carers.

Equity – we know that, at the moment, where you live in Lincolnshire and what your life circumstances are can have an impact on the support you can get, so we are looking at ways in which everyone can access care and support more easily, and make sure people can access support nearer to home.

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To meet these strategic priorities and to help people overcome these challenges:

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

To achieve this, we have set 11 objectives. 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.***

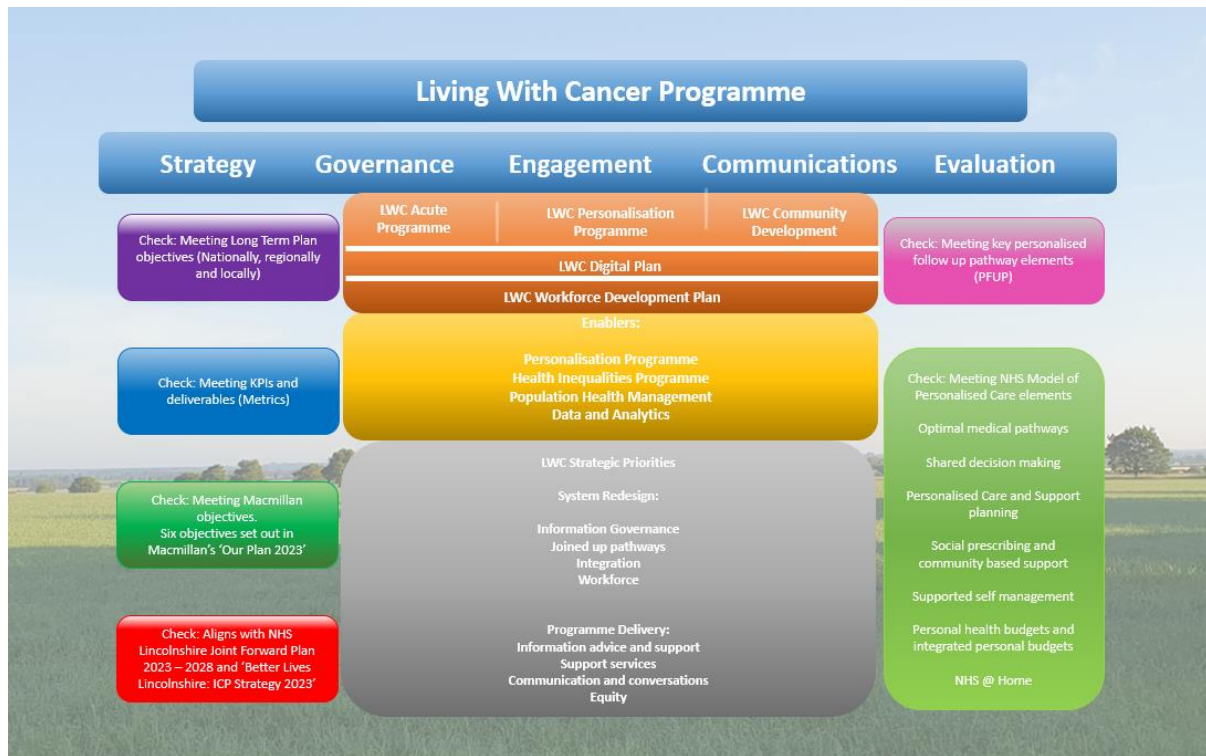
We will use a transformational, whole-system, place-based, asset-based, person-centred approach:

'We are creating a better and sustainable future for supporting people LWC, involving and integrating all relevant parts of the health and social care system, using the assets we already have, supporting people in the place they would like and in the way they would like, and placing people at the centre of everything we do.'

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We will arrange the LWC programme in the following way:



Making our vision a reality

The Lincolnshire Living with Cancer (LWC) Programme is a complex programme with many interdependencies. We are required to meet objectives set locally, regionally and nationally, from across sectors and also meet the needs of our residents.

We have listened to what people living with cancer have told us about the challenges they face to living well after a cancer diagnosis. In this strategy, we show how by meeting our each of our objectives, we will make the changes that people living with cancer in Lincolnshire want to see which we have set as our Living with Cancer strategic priorities.

We have also taken the priorities and objectives that we are required to meet that are set nationally, regionally and system-wide locally, and show how by using the Living with Cancer approach, we will support Lincolnshire Integrated Care System (LICS) to make these a reality. **(Please see appendix 1)**

Our policy and strategic drivers are:

National:

- NHS Long Term Plan 2019⁷
- Macmillan Cancer Support – Our Plan 2023⁸
- NHS Long Term Workforce Plan 2023⁹

Regional

- East Midlands Cancer Alliance priorities.¹⁰

Local

- NHS Lincolnshire Joint Forward Plan 2023 - 2028¹¹
- 'Better Lives Lincolnshire' Integrated Care Partnership Strategy 2023¹²

⁷ [NHS Long Term Plan v1.2 August 2019 \(england.nhs.uk\)](https://www.nhs.uk/longtermplan/long-term-plan-v1-2-august-2019/)

⁸ [Our plan 2023 \(macmillan.org.uk\)](https://www.macmillan.org.uk/our-plan-2023/)

⁹ [NHS Long Term Workforce Plan \(england.nhs.uk\)](https://www.nhs.uk/longtermplan/long-term-workforce-plan-2023/)

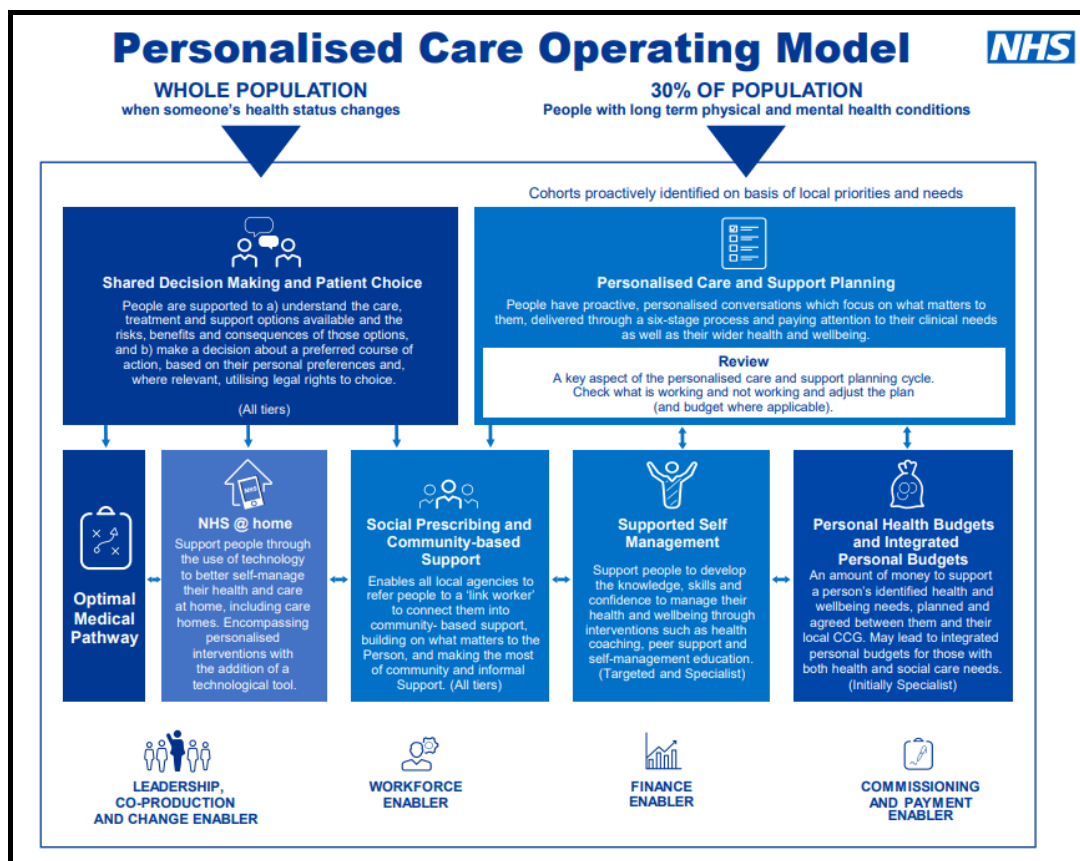
¹⁰ [Living With and Beyond Cancer - East Midlands Cancer Alliance](https://www.eastmidlandsalliance.org.uk/living-with-and-beyond-cancer/)

¹¹ [NHS Lincolnshire Joint Forward Plan 2023-28 \(icb.nhs.uk\)](https://www.lincolnshire.nhs.uk/forward-plan-2023-28/)

¹² <https://lincolnshire.icb.nhs.uk/documents/strategies-and-plans/integrated-care-partnership-strategy/integrated-care-partnership-strategy-january-2023/?layout=default>

- Lincolnshire People Plan 2023 – 2024 (The Lincolnshire Integrated Cancer Workforce Development Strategy 2023 – 2025 aligns to this plan)

Finally, we will ensure the programme meets the elements of the NHS Personalised Care Model:



This strategy is the overarching Living with Cancer Strategy for Lincolnshire. It is supported by two additional strategies which will be adopted concurrently, and these will support the programme to meet its strategic priorities. They are:

- The Lincolnshire Integrated Cancer Workforce Development Strategy 2023 – 2025 – developed in collaboration with United Lincolnshire Hospitals Trust (our Acute provider).
- The Lincolnshire Cancer Digital Strategy 2023 - 2025.

Objective 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.

To make this happen we will:

- Make personalised follow up pathways for breast, prostate, colorectal, endometrial and at least two other cancers business as usual by 2025.
- 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/record/refer/navigate which can be delivered in a variety of settings in acute and the community and at different points on pathways.
- Integrate the LWC Programme into Acute pathways (including Prehabilitation), Primary Care Networks, Locality Teams and wider neighbourhood networks.
- Implement personalisation interventions: holistic needs assessments and personalised care and support plans, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a using a consistent framework with local variance to meet local needs.
- Collaborate with out of county providers to develop pathways of support for their Lincolnshire patients.
- Adopt the Lincolnshire Cancer Digital Strategy 2023 – 2025.

This will help the us meet these LWC Strategic priorities:

Information governance.
Joined up pathways.

This will help implement the NHS Personalisation Model elements:

Optimal clinical pathways

Objective 2

People living with and beyond cancer are active participants in supported self-management.

To make this happen we will:

- Develop and implement a consistent model of triage/record/refer/navigate which can be delivered in a variety of settings in acute and the community and at different points on pathways.
- 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.
- Use existing assets to make sure different levels of need in all health and wellbeing elements 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.
- Adopt the Lincolnshire Cancer Digital Strategy 2023 – 2025.

This will help the us meet these LWC Strategic priorities:

Information advice and support.
Support services.
Equity.

This will help implement the NHS Personalisation Model elements:

Shared decision making
Supported self- management.

Objective 3

People delivering health and social care, work in partnership to facilitate supported self-management.

To make this happen we will:

- Align our work with the Lincolnshire Personalisation, Health Inequalities and Population Health Management Programmes.
- Integrate the LWC Programme into Acute pathways (including Prehabilitation), Primary Care Networks, Locality Teams and wider neighbourhood networks.
- Collaborate with our Integrated Care Partners to improve patient experience and quality of life.
- Work with other long term condition programmes, Primary Care Transformation, Lincolnshire Personalisation Programme, Lincolnshire Health Inequalities Programme and Lincolnshire Population Health Management Programme to transform 'Living Well' for people living with long term conditions including cancer.
- Adopt the Lincolnshire Cancer Digital Strategy 2023 – 2025.

This will help the us meet these LWC Strategic priorities:

Integration.

Workforce.

Communication and conversations.

This will help implement the NHS Personalisation Model elements:

Supported self- management.

Objective 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.

To make this happen we will:

- Make personalised follow up pathways for breast, prostate, colorectal, endometrial and at least two other cancers business as usual by 2025.
- 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/record/refer/navigate which can be delivered in a variety of settings in acute and the community and at different points on pathways.
- Integrate the LWC Programme into Acute pathways (including Prehabilitation), Primary Care Networks, Locality Teams and wider neighbourhood networks.
- Implement all four living with cancer interventions: holistic needs assessments and personalised care and support plans, end of treatment summaries, cancer care reviews and access to health & wellbeing interventions, using a consistent framework with local variance to meet local needs.
- Adopt the Lincolnshire Digital Strategy 2023 – 2025.

This will help the us meet these LWC Strategic priorities:

Information governance.

Joined up pathways.

Integration.

Communications and conversations.

Information advice and support.

Support services.

Equity.

This will support the implementation of these NHS Personalisation Model elements:

Shared decision making.

Personalised care and support planning.

Optimal medical pathways

NHS @ home

Social prescribing and community-based support

Supported self- management.

Personal health budgets (PHBs) and integrated personal budgets (IPBs)

Objective 5

A tested and flexible service delivery model is operational in Lincolnshire.

To make this happen we will:

- Make sure that people's needs are identified in a proactive way by implementing holistic needs assessments in acute pathways, primary care and the community, and make sure people can access a full range of services that support active self-management.
- Map existing assets, use what we already have, identify gaps and where gaps exist, support new services to start which are appropriate to the communities which they serve.
- Work with existing service delivery providers across sectors to come up with innovative delivery solutions to meet health and wellbeing needs of individuals and communities.
- Work with other long term condition programmes, Primary Care Transformation, Lincolnshire Personalisation Programme, Lincolnshire Health Inequalities Programme and Lincolnshire Population Health Management Programme to transform 'Living Well' for people living with long term conditions including cancer.
- Adopt the Lincolnshire Cancer Digital Strategy 2023 – 2025.

This will help the us meet these LWC Strategic priorities:

Support services.

Equity.

This will help implement the NHS Personalisation Model elements:

Supported self- management.

Personalised care and support planning.

Social prescribing and community-based support

Objective 6

A partnership across all stakeholders is established to transform cancer care into a whole systems approach which becomes everyday business.

To make this happen we will:

- Continue to collaborate with our Integrated Care Partners to improve patient experience.
- Work with other long term condition programmes, Primary Care Transformation, Lincolnshire Personalisation Programme, Lincolnshire Health Inequalities Programme and Lincolnshire Population Health Management Programme to transform 'Living Well' for people living with long term conditions including cancer.
- work with the Continuing Health Care Team and other teams in Lincolnshire, to explore ways in which people living with cancer can access PHBs and IPBs
- Adopt the Lincolnshire Cancer Digital Strategy 2023 – 2025.

This will help the us meet these LWC Strategic priorities:

Information governance.
Joined up pathways.
Integration. Workforce.
Communications and conversations.
Information advice and support.
Support services.
Equity.

This will help implement the NHS Personalisation Model elements:

Shared decision making.
Personalised care and support planning.
Optimal medical pathways
NHS @ home
Social prescribing and community-based support
Supported self- management.
Personal health budgets (PHBs) and integrated personal budgets (IPBs)

Objective 7

The programme is co-designed with patients, the public and stakeholders.

To make this happen we will:

- Support our existing Co-production Groups and the Cancer Expert Reference Group and make sure that they continue and are able to co-produce parts of the 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.

This will help the us meet these LWC Strategic priorities:

Equity

Objective 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.

To make this happen we will:

- Set annual key performance indicators.
- Implement the recommendations of and build on the Living with Cancer Evaluation Programme carried out in 2023.
- Ensure that reports from the Quality of Life and National Cancer Patients' Experience Surveys are actioned to improve patient experience and quality of life.
- Use data, engagement and the Living with Cancer Dashboard to demonstrate the impact of the Living with Cancer Programme.
- Adopt the Lincolnshire Cancer Digital Strategy 2023 – 2025.

This will help the us meet these LWC Strategic priorities:

Integration.
Equity.

Objective 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.

To make this happen we will:

- Adopt the Lincolnshire Integrated Cancer Workforce Development Strategy 2023 – 2025.
- Work with our Integrated Care Partners to grow the workforce, embed the right culture and improve retention and work and train differently to support people living with cancer.

This will help the us meet these LWC Strategic priorities:

Workforce.

Equity.

This will help implement the NHS Personalisation Model elements:

Personalised care and support planning

Social prescribing and community-based support

Objective 10

The programme aligns and integrates with other strategic, organisational and operational developments locally.

To make this happen we will:

- Align the Living with Cancer Programme with NHS Long Term Plan 2019, NHS Workforce Plan 2023, Macmillan Cancer Support – Our Plan 2023, NHS Long Term Workforce Plan 2023, East Midlands Cancer Alliance priorities, NHS Lincolnshire Joint Forward Plan 2023 - 2028, 'Better Lives Lincolnshire' Integrated Care Partnership Strategy 2023
- Work with other long term condition programmes, Primary Care Transformation, Lincolnshire Personalisation Programme, Lincolnshire Health Inequalities Programme and Lincolnshire Population Health Management Programme to transform 'Living Well' for people living with long term conditions including cancer.
- Adopt the Lincolnshire Integrated Cancer Workforce Development Strategy 2023 – 2025.
- Adopt the Lincolnshire Cancer Digital Strategy 2023 – 2025.

This will help the us meet these LWC Strategic priorities:

Information governance.
Joined up pathways.
Integration.
Workforce.
Communications and conversations.
Information advice and support.
Support services.
Equity.

This will help implement the NHS Personalisation Model elements:

Shared decision making.
Personalised care and support planning.
Optimal medical pathways
NHS @ home
Social prescribing and community-based support
Supported self- management.
Personal health budgets (PHBs) and integrated personal budgets (IPBs)

Objective 11

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

To make this happen we will:

- we will create a better and sustainable future for supporting people living with cancer, involving and integrating all relevant parts of the health and social care system, using the assets we already have, supporting people in the place they would like and in the way they would like, and placing people at the centre of everything we do.

This will help the us meet these LWC Strategic priorities:

Information governance.
Joined up pathways.
Integration.
Workforce.
Communications and conversations.
Information advice and support.
Support services.
Equity.

This will help implement the NHS Personalisation Model elements:

Shared decision making.
Personalised care and support planning.
Optimal medical pathways
NHS @ home
Social prescribing and community-based support
Supported self- management.
Personal health budgets (PHBs) and integrated personal budgets (IPBs)

How will we measure our success?

There are a number of targets that we must achieve, and these are set nationally and regionally. We have to report our progress on these targets to East Midlands Cancer Alliance who then report to NHS England. We are given local choice as to how we approach meeting these targets.

People living with cancer in the county have told us about the challenges that they face to live well after a cancer diagnosis, and these have informed our strategic priorities.

Our evaluation team have given us recommendations for improvement following an evaluation of the programme in spring 2023.

Lincolnshire ICB and United Lincolnshire Hospitals Trust (ULHT) receive reports on patient experience annually from the National Cancer Patient Experience Survey (NCPES) and the Cancer Quality of Life (QoL) survey.

We have set 12 'Key Performance Indicators' KPIs for ourselves to keep track of and measure our progress towards meeting our targets¹³.

We have developed a 'Living with Cancer Dashboard' which enables us to measure our performance the impact of the programme.

We will:

- report to Living with Cancer Board and Cancer Board to update on our progress.
- use the Lincolnshire ICB project and programme management system (Aspyre) to plan our work and manage our progress.
- review the programme and projects in March 2024 and develop plans for 2024 – 2025.
- use the Living with Cancer dashboard to track our progress towards meeting our KPIs and show the impact of the programme.
- review our KPIs in March 2024 and reset for 2024 – 2025.
- report every 3 months to East Midlands Cancer Alliance on progress towards our targets.
- Every year, we will produce an action plan to show how we are going to improve scores from the NCPES and QoL Survey.
- Carry out the recommendations from our evaluation report.

¹³ See appendix 3.

The future: a forward view to 2028.

This strategy is aligned to the two local system strategies '**Better Lives Lincolnshire**' **Integrated Care Partnership Strategy 2023** and **NHS Lincolnshire Joint Forward Plan 2023 – 2028**. The second of these documents is a five-year plan.

As well as setting our agenda for 2023 – 2025, the programme is also looking forward to 2028 to make sure that we evolve in-step with wider system plans. This enables us to remain flexible to meet changing national priorities, whilst continuing to plan for the future.

Our approach to supporting people living with cancer in our rural county is recognised as being effective and our ways of working could be used to support people with cancer and other health conditions or diseases, and people with other long-term conditions. As a result, many of our roles have secured recurrent system funding.

In response to this system investment, we will:

- year on year develop programmes plans and demonstrate the impact of our work.
- work with other long term condition programmes, Primary Care Transformation, Lincolnshire Personalisation Programme, Lincolnshire Health Inequalities Programme and Lincolnshire Population Health Management Programme to transform 'Living Well' for people living with long term conditions including cancer.
- work with the ULHT Patient Initiated Follow Up (PIFU) programme to identify points on other specialities' pathways where LWC models of working could be applied.
- develop a sustainable Prehabilitation in cancer model and explore ways of implementing this for other specialities.
- Collaborate with the University of Lincoln and share our practice and knowledge regionally, nationally and internationally.

Appendix 1: Strategic alignment

The following matrix shows how the Lincolnshire Living with Cancer Programme aligns to national, regional, and local strategy and policy.

NHS Long term plan 2019 and East Midlands Cancer Alliance priorities:

- Where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.
- After treatment, patients will move to a follow-up pathway that suits their needs and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred.
- Support the implementation of the annual National Cancer Patient Experience Survey (NCPES).
- Promote and support the delivery of the Cancer Quality of Life Survey and use data to inform service improvement.
- Stronger NHS action on health Inequalities.
- All patients, including those with secondary cancers, will have access to the right expertise and support, including a Clinical Nurse Specialist or other support worker.

Macmillan Cancer Support – Our Plan 2023:

- Everyone with cancer will know that they can turn to Macmillan from the moment they are diagnosed, and how we can help them.
- 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 will reflect and represent the communities we serve in everything we do to support everyone living with cancer.

NHS Lincolnshire Joint Forward Plan 2023 – 2028 Aims:

- Priority 1: A new relationship with the public.
- Priority 2: Living well and staying well.
- Priority 3: Improving access.
- Priority 4: Integrated community care
- Priority 5: A happy and valued workforce

‘Better Lives Lincolnshire’ Integrated Care Partnership Strategy 2023

Aims:

- Have a focus on prevention and early intervention.
- Tackle inequalities and equity of service provision to meet population needs.
- Deliver transformational change in order to improve health and wellbeing.
- Take collective action on health and wellbeing across a range of organisations.

Priority enabler 1: Population health and prevention.

- Theme 3: Working age (16-64)
- Theme 4: Ageing well.

Priority enabler 2: Workforce and skills.

- Theme 2: To train and support people who are already working, or seeking jobs, so they gain the skills needed to take up future job vacancies.

Priority Enabler 3: Personalisation.

- Theme 1: Shared decision-making and ‘What matters to you?’ conversations.
- Theme 2: Supported self-care and self-management
- Theme 3: Wellbeing, social prescribing, and community-based support

Priority enabler 4: Community engagement and involvement.

- Theme 1: Consultation, engagement and collaboration
- Theme 2: Community networks
- Theme 3: Volunteering
- Theme 4: Funding for our communities Theme 5: Tools and data

Priority enabler 5: Data and Information Systems

- Theme 1: Supporting people.
- Theme 2: Supporting health and care professionals.

Living with Cancer Programme Strategic alignment	Objective 1: Joined up pathways	Objective 2: Self management	Objective 3: Partnership working	Objective 4: personalisation.	Objective 5: working model	Objective 6: Whole System approach	Objective 7: Co-design	Objective 8: Evaluation and measurement	Objective 9: Workforce	Objective 10: Integration	Objective 11: Patient experience
NHS Long term plan 2019 and East Midlands Cancer Alliance priorities:											
Where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.											
After treatment, patients will move to a follow-up pathway that suits their needs and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred.											
Support the implementation of the annual National Cancer Patient Experience Survey (NCPES).											
Promote and support the delivery of the Cancer Quality of Life Survey and use data to inform service improvement.											
Stronger NHS action on health inequalities.											
All patients, including those with secondary cancers, will have access to the right expertise and support, including a Clinical Nurse Specialist or other support worker.											
NHS Long Term Workforce Plan 2023:											
Train.											
Retain.											
Reform.											
Macmillan Cancer Support – Our Plan 2023:											
Everyone with cancer will know that they can turn to Macmillan from the moment they are diagnosed, and how we can help them.											
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 will improve 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.											
NHS Lincolnshire Joint Forward Plan 2023 – 2028 Aims:											
Priority 1: A new relationship with the public.											
Priority 2: Living well and staying well											
Priority 3: Improving access											
Priority 4: Integrated community care											
Priority 5: A happy and valued workforce											
Better Lives Lincolnshire' Integrated Care Partnership Strategy 2023											
Have a focus on prevention and early intervention.											
Tackle inequalities and equity of service provision to meet population needs.											
Deliver transformational change in order to improve health and wellbeing.											
Take collective action on health and wellbeing across a range of organisations.											
Priority enabler 1: Population health and prevention.											
Theme 3: Working age (16-64)											
Theme 4: Ageing well											
Priority enabler 2: Workforce and skills.											
Theme 2: To train and support people who are already working, or seeking jobs, so they gain the skills needed to take up future job vacancies.											
Priority Enabler 3: Personalisation.											
Theme 1: Shared decision-making and 'What matters to you?' conversations.											
Theme 2: Supported self-care and self-management											
Theme 3: Wellbeing, social prescribing, and community-based support											
Priority enabler 4: Community engagement and involvement.											
Theme 1: Consultation, engagement and collaboration											
Theme 2: Community networks											
Theme 3: Volunteering											
Theme 4: Funding for our communities Theme 5: Tools and data											
Priority enabler 5: Data and Information Systems											
Theme 1: Supporting people.											
Theme 2: Supporting health and care professionals.											

Appendix 2: Patient, public and staff engagement 2023.

The last major living with cancer engagement programme was carried out in 2016 – 2017. This enabled us to understand the needs of people living with cancer in the county, and those who care for them, and from that set our strategic priorities.

For this strategy, we needed to understand what had changed since 2017, and identify whether the needs of people living with cancer had changed. Between February and April 2023, we carried out another large-scale engagement programme. The methodology we used was a patient and public on-line survey and a staff on-line survey. We had face to face conversations with people living with cancer via cancer support groups in the county and a workshop on 21st April 2023 for colleagues from different sectors across the Lincolnshire system and also members of our cancer co-production groups and Cancer Expert Reference Group.

We would like to thank the Macmillan Living with Cancer Co-production Group who helped us define the survey questions, and Lincolnshire ICB Engagement Team who ran the survey, promoted the survey, carried out the face-to-face conversations and analysed the survey results for us.

We would also like to thank the 356 people living with and affected by cancer and 43 staff members in the county who gave their time to tell us their stories. Their experience is at the heart of this strategy, and they continue to drive our work.

For more information about the LWC Survey and survey results please contact licb.lincscancer@nhs.net

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Appendix 3: Governance of programme, action plan 2023 – 2025 and progress reporting.

Programme and project action plans for 2023 – 2024 have been developed and uploaded onto the Lincolnshire ICB programme management system Aspyre.

Progress is reported on a bi-monthly basis to Living with Cancer Board, monthly to Lincolnshire ICS Cancer Board and quarterly to East Midlands Cancer Alliance via quarterly reports.

Annually, the programme reports on progress to Lincolnshire County Health and Social care Committee.

Data is collected on an ongoing basis to populate the Living with Cancer Dashboard to demonstrate impact.

Appendix 4: Key Performance Indicators 2023 – 2024, Living with Cancer Outcomes Framework.

60% of all newly diagnosed patients within ULHT will be offered a HNA within 31 days of being informed of their cancer diagnosis by April 2023. This will increase to 75% by March 2024.	40% of all patients having chemotherapy treatment within ULHT will be offered a “during treatment HNA” following their 3rd or 4th cycle by March 2024.	6 tumour pathways (Prostate, Breast, Lymphoma, Colo-rectal, Endometrial & Thyroid) will ALL have a standardised end of treatment summary template finalised for each stratified pathway by March 2024.	By Dec 2023 50% of patients under secondary care, who identify a need for P&E support (HNA score of 5 or above) will be assessed using a PHQ9 & GAD7 assessment tools and then signposted or referred to an appropriate support service which meets their needs.
By Sept 2023 PFUP will be embedded into Breast, Colorectal, Prostate and Endometrial pathways.	By December 2023 increased number of patients by 15% who are placed on a personalised stratified follow up pathway in breast, colorectal, endometrial and prostate	By March 2024 have PFUP embedded into Thyroid and Lymphoma	By December 2023 increase in EOT HNA's offered by 15% in Breast, Prostate, Colorectal and Endometrial.
By March 2024 75% of patients completing a L4 Psychological support intervention report an improvement in their psychological distress.	By March 2024, the LWC Team provide an initial response to 85% of community, out of county and vulnerable pre-diagnosis requests for holistic support within 2 working days	By October 2023 50% of Lincolnshire GP practices will have been offered a dedicated CCR training package.	By the end of March 2024 50% of GP practices will have had delivery of a dedicated CCR training package.

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 2025 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 effectiveness for the experience of patients, carers and significant others, including the service and the wider health and care system. 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 'places', in that it promotes and develops services which support people in their places.	The programme promotes Self Care principles	The programme adopts an Asset Based Community Development approach	The programme is delivered embracing innovation
TIMESCALE	31/03/2025	31/03/2025	31/03/2025	31/03/2025	31/03/2025	31/03/2025	31/03/2025	31/03/2025	31/03/2025	31/03/2025								
STRATEGIC PRIORITIES	Communication and conversations Tackling inequality Access to information, advice and support Information governance Integration Service development Pathways Workforce																	
METRICS	Personalised Follow up Pathways Four LWC interventions - HNA, TS, CCR & Health & Wellbeing Improvement in patient experience (QoL and National Patient Experience Survey)																	

Appendix 5: Lincolnshire Living with Cancer achievements 2021 – 2023.

2021 - 2023 Actions	Progress 2021-2023	How achieved
Develop personalised follow up pathways for breast, prostate, colorectal, endometrial and two other cancers by 2022.	In progress	Remote monitoring module installed on Somerset. Working with teams to embed in practice.
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.	Achieved	Personalisation model developed which can be used at other points on pathways, in different settings and different staff groups.
Use this learning to develop personalised follow up pathways for other cancers.	In progress	Working with Lymphoma and Thyroid teams as next priority pathways
Develop and implement a consistent model of triage/navigate/refer/record which can be delivered in a variety of settings.	In progress	Personalisation model developed which can be used at other points on pathways, in different settings and different staff groups.
Integrate the LWC Programme into Acute pathways, Primary Care Networks, Neighbourhood Working Teams and wider neighbourhood networks.	Achieved	Community cancer Co-ordinators attend all community multi disciplinary teams. All PCNs have been engaged.
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.	In progress	Programme taking place via Acute, Personalisation and Community Development programmes. Workforce and Digital workstreams
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.	Achieved	Lincolnshire Cancer Support website live on 8th June 2022. 1400+ assets mapped and shared with Lincolnshire Connect to Support Website. 2 new support groups started for Secondary Breast Cancer and Kidney Cancer.
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.	In progress	Services available for all levels of psychological distress in all parts of the county. Fighting Fit sessions in Lincoln (x2) Boston, Mablethorpe, Gainsborough and Grantham. On-line support for Financial concerns on Lincolnshire cancer support website. Radiotherapy Late effects service started, and Consequences of Treatment Clinic for Upper Gastrointestinal Cancers.
Make sure that people's needs are identified in a proactive way by implementing holistic needs assessments and personalised care plans	In progress	Monthly engagement with all CNSs in ULHT and training available for HNAs and care planning.
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.	In progress	Services available for all levels of psychological distress in all parts of the county. Fighting Fit sessions in Lincoln (x2) Boston, Mablethorpe, Gainsborough and Grantham. On-line support for Financial concerns on Lincolnshire cancer support website. Radiotherapy Late effects service started, and Consequences of Treatment Clinic for Upper Gastrointestinal Cancers. Lincolnshire Cancer Support website live on 8th June 2022. 1400+ assets mapped and shared with Lincolnshire Connect to Support Website. 2 new support groups started for Secondary Breast Cancer and Kidney Cancer.
Align our work with the Lincolnshire Personalisation Programme.	Achieved	Team active in Personalisation Programme network. Programme aligned to NHS Model of Personalisation.
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.	In progress	Lincolnshire LWC Workforce Development Strategy 2021 - 23 adopted and enacted. Lincolnshire Integrated Cancer Workforce Development Strategy 2023 - 25 to be adopted September 2023.
Work with existing service delivery providers to come up with innovative delivery solutions for example the Fighting Fit Programme.	In progress	Services available for all levels of psychological distress in all parts of the county. Fighting Fit sessions in Lincoln (x2) Boston, Mablethorpe, Gainsborough and Grantham. On-line support for Financial concerns on Lincolnshire cancer support website. Radiotherapy Late effects service started, and Consequences of Treatment Clinic for Upper Gastrointestinal Cancers. Lincolnshire Cancer Support website live on 8th June 2022. 1400+ assets mapped and shared with Lincolnshire Connect to Support Website. 2 new support groups started for Secondary Breast Cancer and Kidney Cancer.
Integrate the Living with Cancer programme into the Lincolnshire Integrated Care System by 2023.	Achieved	7 roles secured recurrent funding from Lincolnshire ICB and 1 role from ULHT.
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.	In progress	Initial discussions have taken place. New strategy aligns with local strategies.
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.	Achieved	Additional funding secured for transition of Co-Production Groups to support from ICB. 10 staff members being trained in Co-Production support.
Support the establishment of new LWC Co-Production groups in different parts of the county, and with different cohorts of patients.	In progress	Co-production approach being implemented in health inequalities in bowel cancer screening.
Develop a refreshed Living with Cancer communications and engagement plan so that people can be involved in the programme.	Achieved	Engagement programme for Strategy development February - April 2023.
Work with the ULHT Expert by Experience Programme and patient Experience team to establish a Cancer Patient Panel.	Achieved	Cancer Expert Reference Group established May 2022.
Implement the recommendations of and build on the Living with Cancer Evaluation Programme carried out in 2020	Achieved	Use of data improved. Delivery of programme 2021 - 2023 with evidenced outcomes.
Carry out a further evaluation at the end of the external funding in 2023.	Achieved	Funding secured for further evaluation carried out in spring 2023.
Ensure that recommendations from the Quality of Life and National Cancer Patients' Experience Surveys are carried out.	In progress, on going	Action plans developed following 2021 and 2022 survey reports
Develop a Living with Cancer People Plan and make sure it aligns with the Lincolnshire ICS People Plan.	Achieved	Lincolnshire LWC Workforce Development Strategy 2021 - 23 adopted and enacted. Lincolnshire Integrated Cancer Workforce Development Strategy 2023 - 25 to be adopted September 2023.
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.	In progress ongoing	
Support the creation and longevity of new roles if necessary.	In progress	6 Cancer Care Co-ordinators in Boston PCN. Supporting business cases for roles in ULHT. Secured macmillan funding for new Project Manager to scope and develop model for Macmillan advice in the community and eHNA delivery.
Work closely with Macmillan Cancer Support, East Midlands Cancer Alliance and NHS England to make sure we meet local, regional and national objectives.	Achieved	See all achievements
Make the most of our digital assets, and make sure everything we do aligns with the Lincolnshire ICS digital plan.	Achieved	Adoption and enactment of Cancer Digital Strategy 2021 - 23 and development of Cancer digital Strategy 2023 - 25. Website live, Remote Monitoring Module live in ULHT. 1400+ assets mapped and shared with Lincolnshire Connect to Support Website.

Appendix 6: Case studies

Case Study 1: Libby Stennett Community Cancer Care Co-ordinator in the Living with Cancer Team

A 47-year-old female patient was brought to the attention of the Community Cancer Care Coordinators in May 2023, by a breast CNS who had concerns regarding the patient's wellbeing. This lady is single, has four children under the age of 14, has no support and no transport.

The initial request came through to find a way of supporting this lady to attend appointments. It then became quite clear that this was a complicated case that evolved to become even more complex and concerning.

This all began when this lady was diagnosed with stage 4 breast cancer in early April 2023. She attended her results appointment with the eldest and youngest children (a fourteen-year-old and a toddler) and insisted on the children being present when she was told her results. The teenager became very upset and emotional. The CNS wondered if the patient was leaning on them as a carer.

The patient then did not attend an appointment later in April and according to the CNS had since "gone to ground" not answering or responding to calls or letters and had completely disengaged with the team. The CNS was concerned this was due to the patient not having support with the children to attend appointments.

Without treatment this lady is palliative with less than 12 months to live. She urgently needed an echocardiogram (a pre-requisite to starting chemo).

The CCCCs brought this case to the Neighbourhood Team, the Health Visitor (who said they were unable to help as they, only had contact with the youngest child some time previously). The GP surgery was asked to make urgent contact with the patient, but the surgery said they were only dealing with emergencies.

The CCCCs emailed the PCN Lead and the patient's GP directly asking that contact be made with the patient.

As a result, a mini-MDT was arranged between the CNS, GP surgery, Neighbourhood team and the CCCCs. Background information was obtained, helping the professionals involved to understand the patient's background, present situation and her possible reluctance to engage with treatment. The patient originally came to the UK unofficially and was at that time being investigated by the Home Office. She married her abusive partner in order to remain in the UK and had 3 children by him. She remained in the relationship until her case with the Home Office was resolved. She then requested help for herself and the children to be taken to safety. She was rehoused and moved from the West Midlands to Lincolnshire. The youngest child was the result of a subsequent relationship which has now ended and there is no contact with the child's father.

Was the patient worried about losing her children? What would happen to these four children should the patient not engage with her treatment?

The GP contacted the patient, who was feeling overwhelmed and could not cope with too many people contacting her. However, although contact had been made, there was still an urgency not to delay the start of treatment further. The GP invited the patient into the surgery, where she agreed to re-engage and for a referral to Children's Social Services to be made.

An agreement was made for all contact to go via the GP to prevent the patient from feeling so overwhelmed. A neighbour of the patients also came forward and offered some help and transport to hospital.

The Children's services referral was accepted for a section 17 needs assessment to be completed.

It then became apparent that the patient was worried financially and had built up a substantial debt on the electricity meter. The CCCC's ensured a referral to the St Barnabas Welfare and Benefits team was made and they contacted an energy advisor in CAB. As a result, weekly payments to the debt were reduced and a greater percentage of the payment was to go to the electricity use itself. She was also issued with emergency energy vouchers totalling £60.00.

The patient attended an echocardiogram in June and then began chemo in July. She became ill after her first session resulting in an ambulance call out. The CCCC's collaborated with the Chemo department and the neighbourhood team to investigate the events and to make sure the patient had access to the Oncology Triage line and cancer ward for any out of hours worries.

The patient is still undergoing chemotherapy with a view to surgery in the future.

Result/Support provided:

1. The patient re-engaged with treatment.
2. The children were safe-guarded and supported by their schools.
3. A strong relationship was built between the GP and the patient.
4. Support in terms of childcare and transport was successfully put in place.
5. Financial assistance and advice were given.
6. HNAs were carried out by the team in chemo on an ongoing basis.
7. Problems were identified and resolved promptly saving further DNAs and disengagement.
8. The chemotherapy coordinator has continued to support the patient all the way through her treatment which is ongoing. The coordinator has built up a strong relationship with the patient. There is a strong support mechanism in place as the patient continues with her treatment

Case Study 2: Anna Chapman Community Cancer Care Co-ordinator in the Living with Cancer Team

This patient is a 57-year-old, non-English speaking, male with metastatic prostate cancer. The patient was brought to the attention of the Community Cancer Care Coordinator for Southeast Lincolnshire during a Neighbourhood Working Team Multi-Disciplinary Team (MDT) during Summer 2023.

The patient first came under the care of the local acute hospital in November 2022, with a diagnosis of metastatic prostate cancer. It is unclear whether the patient had been previously diagnosed in his home country prior to this as his English is very limited and although he has family the patient lives alone and it is believed that his family are still living outside of the UK and visit infrequently. The patient also has a long history of mental illness and there is evidence to suggest that he has been sectioned on several occasions prior to moving to the UK.

Until early 2023 the patient was under the care of the Acute Urology Team and although he had received a palliative diagnosis which he was struggling to accept, he was believed to be relatively stable. However, by summer 2023 his attendance at Urology outpatient appointments and for blood tests and medication reviews with his GP practice had become sporadic, and on the rare occasions that he did present his physical and mental condition appeared to be deteriorating rapidly. As a result of his decline the patient was presented for discussion at the Boston Neighbourhood Working Team MDT by several health care professionals who had, had recent contact with him and were concerned about his uncontrolled and unmanaged pain, and general wellbeing.

During the MDT the Palliative Nursing Teams in attendance reported that the patient was displaying aggressive, erratic behaviour towards them, which had resulted in them visiting in pairs. He was sleeping on an air bed in his living room as he was unable to get in and out of bed and presented as a falls risk. He was in severe unmanaged pain and was losing weight rapidly, and in addition to this was having problems with eating and going to the toilet. The patient was also periodically not letting individuals enter his property to check on his welfare.

Due to several DNA appointments neither the Urology nor Medical Oncology teams had seen him for several months and as he had an outpatient's appointment scheduled with Medical Oncology the following week it was decided that the team's priorities should be to; ensure his attendance at his upcoming outpatient appointment, and that community teams meet with a member of his acute care team to discuss their concerns as soon as possible.

It was agreed that the Community Cancer Care Coordinator would arrange hospital transport to and from the appointment via EMAS and make a referral for fast-track funding to support an enhanced homecare package. The patients GP also agreed to speak to the patient and offer him support with attending this outpatient appointment.

The Community Cancer Care Coordinator suggested a 'mini-MDT' prior to the outpatient's appointment to facilitate joined up working between acute and community care providers, and to help the community teams better understand the patient's diagnosis and prognosis. This would also allow community teams to convey their concerns about the management of his disease whilst in the community. The MDT was scheduled and was attended by representatives from the patient's GP practice, Community Occupational Health, Specialist Neighbourhood Practitioners, Palliative Nursing Teams, the patient's acute care team, and the Community Cancer Care Coordinator. As a result of the mini-MDT, the attending Acute Urology CNS agreed to urgently contact the patient's Medical Oncologist outlining the concerns of the community teams and asking for new diagnostic imaging to be performed to ascertain disease progression and facilitate the creation of a practical and robust care plan for symptom management.

The patient was collected by EMAS transport and taken to his Medical Oncology outpatient appointment as arranged and was assessed upon arrival and found to be so unwell that he was immediately admitted as an in-patient for imaging and treatment. Scans showed that the patient had metastatic liver and bone metastases with disease progression that included spine, pelvis, skull and renal problems.

He also had metastatic spread to his left femur, which was considered a high risk of fracture, and the Orthopaedic team reviewed the patient to determine if he could be a candidate for a surgical procedure to stabilise his femur.

Unfortunately, the patient declined any surgery but remained in hospital for ten days, before being discharged back to his home with a fast-track funded package of care, scheduled palliative radiotherapy, syringe driver medication to adequately manage his pain, anticipatory medication, and a completed RESPECT form.

The patient's prognosis is estimated to be approximately 3 months, and he remains challenging requiring high levels of physical and emotional support. It is the belief of both the community and acute teams that his behaviour is a consequence of both a pre-existing mental health condition and disease progression to the brain and teams are working closely to support both him and one another with managing this. The Community Cancer Care Coordinator has recently acquired a walking frame for the patient to allow him to mobilise and minimise his risk of falls and fracture of the femur, and free hospital transport will be arranged for him in advance of any upcoming medical appointments that he needs to attend.

As a direct result of the Cancer Team, Neighbourhood Working Team, Community Palliative Nursing Team and the Acute Urology and Oncology Teams interventions the patient was picked up at a point of crisis in the community and received the hospital inpatient treatment that he required to stabilise his condition sufficiently, enabling him to return to his home in a safe and supported way.

The patient is now being monitored closely by his GP and community nursing teams and is being discussed at primary care, acute and Neighbourhood MDTs on a weekly basis enabling teams to react swiftly to any changes in his condition.

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There is regular communication between acute and community teams which did not previously exist, and all teams involved with his care are committed to ensuring that the patient is able to remain in his home, in a pain free, dignified manner for as long as possible.

Outcomes for the patient.

Managed and controlled pain.

Better supported care in the home, allowing him to continue to live independently.

Closer monitoring by his GP and Oncologist over the coming months.

The development of an agreed care plan and RESPECT form outlining his wishes.

Support managing his mental health.

Supported transport to medical appointments.

Outcomes for Health Care Professionals.

Improved communication and dialogue amongst teams.

Staff feel safer and better supported in their roles.

Staff are given an opportunity to discuss concerns and seek guidance about the patient regularly and with practitioners outside of their immediate teams.

Although a patient with complex needs, staff feel that they are providing a better standard of palliative care.

Case Study 3: Chloe North Community Cancer Care Co-ordinator in the Living with Cancer Team

A Lincolnshire Neighbourhood Working Team requested support for a male patient who was living with prostate cancer. He was being treated out of county and was struggling to understand his next steps and how he would balance his treatment and the care of his wife as he was her main carer. His wife was experiencing memory and mobility issues and they had not yet received any community support.

The Neighbourhood Team reached out to the Community Cancer Care Co-ordinator during a Multi-Disciplinary Team meeting, as they were struggling to access clinical information about his diagnosis, prognosis, and care plan. With a partnership approach the Neighbourhood Working Team and Community Cancer Care Co-ordinator arranged for the patient to receive referrals to Adult Social Care, the Primary Care Network, Occupational Therapy and Carers First. Alongside this, the Neighbourhood Working Team picked up his wife's referral and scheduled a home visit to review her frailty and overall wellbeing.

Meanwhile, the Community Cancer Care Co-ordinator began investigating his oncology care with the out of county hospital trust, feeding information back to the Neighbourhood Working Team. This included possible consideration for radiotherapy, pending appointments, potential discharge from urology to oncology and beginning hormone therapy.

During consultation at an outpatient appointment, the patient expressed concerns about leaving his wife for long periods of time and declined radiotherapy out of county. As a result of this conversation the Community Cancer Care Co-ordinator worked with the out of county hospital and United Lincolnshire Hospitals Trust to offer transfer of care, including radiotherapy, to Lincolnshire. The patient consented to treatment within Lincolnshire as he would be closer to his wife. This was not straight forward process and required continuous monitoring and follow ups with the relevant teams to ensure the referral was completed.

In the interim, the Community Cancer Care Co-ordinator provided information on referrals for additional support closer to home including grocery and prescription deliveries, dementia support services and counselling services.

Follow ups with the clinical teams resulted in a telephone appointment and offer of Radiotherapy in Lincolnshire, with Adult Social Care providing support to his wife during his treatment times. Once Adult Social Care had provided the support required, the patient was able to begin attending these appointments within Lincolnshire; this intervention has prevented the patient from becoming palliative.