*Improving Cancer Services*

# Late Effects of Radiotherapy Intelligence Framework

*Draft Strategic Discussion Paper | Version 2.0*

For Stakeholder Review and Contribution

# Programme Overview

The Late Effects of Radiotherapy (LER) Intelligence Programme is designed to help NHS organisations better understand the long-term physical, emotional and functional consequences experienced by cancer survivors following radiotherapy treatment. Using the National Cancer Quality of Life Survey (CQOLS), together with cancer prevalence, treatment and population datasets, the programme identifies indicators associated with potential late effects burden and estimates where support services may be most needed.

Radiotherapy is among the most effective cancer treatments available and plays a critical role in improving survival across a wide range of cancer types. As survival rates improve, however, increasing numbers of people are living for years and decades following treatment, and a significant proportion of them experience lasting consequences that were caused or accelerated by the radiotherapy they received. These consequences — collectively described as late effects of radiotherapy — can be severe, debilitating and, in many cases, addressable with the right support. The aim of this programme is to move beyond treating cancer alone and to ensure that people who survive it receive appropriate, evidence-informed support for the long-term consequences of their treatment.

# Executive Summary

## Radiotherapy: Success and Its Consequences

Radiotherapy is delivered to a substantial proportion of all cancer patients in England and contributes meaningfully to improved survival across many tumour types. It is a treatment whose effectiveness in eliminating or controlling cancer is well established and whose role in the therapeutic landscape continues to evolve. For many patients, radiotherapy is the intervention that makes survival possible. It is, by any measure, a success story.

Yet the consequences of radiotherapy do not end when treatment ends. For a significant proportion of patients, the damage that radiotherapy inflicts on healthy tissue alongside tumour tissue produces lasting effects that emerge gradually in the months and years following treatment. These late effects can include chronic bowel and bladder dysfunction, sexual health consequences, lymphoedema, musculoskeletal changes, fatigue, pain and a range of emotional and psychological difficulties. They are not rare. Evidence from published literature and NHS survivorship data suggests that a substantial proportion of radiotherapy-treated cancer survivors — particularly those who received pelvic radiotherapy — experience late effects that meaningfully affect their quality of life. Analyses using evidence-informed estimation models suggest that, for pelvic cancer types, between 32% and 60% of treated patients may experience any late effects, and between 7% and 18% may experience severe late effects. For many of these patients, their experience remains unacknowledged, uninvestigated and unsupported.

## An Intelligence Gap

Despite the scale of this challenge, the NHS currently lacks the systematic intelligence infrastructure needed to understand late effects burden at population level, to identify where it is concentrated, or to target support effectively. Traditional cancer intelligence systems were designed to measure diagnosis, treatment activity and survival. They were not designed to capture what happens to patients in the years after treatment concludes, and they do not — in their current form — provide the patient-centred intelligence that is needed to plan, commission and deliver late effects services.

The National Cancer Quality of Life Survey (CQOLS) offers a partial but important solution to this problem. By capturing patient-reported outcomes directly from cancer survivors, CQOLS provides a window into lived experience after treatment that no clinical dataset currently offers. It cannot diagnose late effects, and it does not yet capture radiotherapy treatment variables in a form that allows direct attribution of symptoms to radiotherapy specifically. But it does capture, at scale and in a form that can be analysed by organisation, cancer type and patient group, the domains in which radiotherapy-treated cancer survivors are reporting the greatest difficulties. This intelligence, combined with evidence-informed estimation models that translate patient volumes and cancer-type-specific incidence

assumptions into approximate burden estimates, creates a practical and actionable framework for LER service planning.

## What This Framework Proposes

This paper sets out how CQOLS data, cancer prevalence intelligence and associated NHS datasets can be used to build a systematic, action-oriented intelligence framework for late effects of radiotherapy. The framework is designed to operate at Trust, Cancer Alliance and Integrated Care Board level, providing organisations with the intelligence they need to understand the likely scale of LER burden within their patient populations, to identify where that burden is greatest, and to prioritise the development of services and support accordingly.

The framework does not seek to establish definitive clinical diagnoses at population level. Instead, it seeks to identify signals of unmet need — to make visible what has previously been invisible — and to provide a basis for the clinical and organisational conversations from which better services for late effects patients can emerge.

## The Opportunity

The opportunity is significant. Late effects of radiotherapy are common, often severe and frequently unaddressed. Many of the consequences that patients experience are amenable to intervention: specialist late effects clinics, pelvic health physiotherapy, bowel and bladder rehabilitation, psychological support, and better-coordinated follow-up pathways can all make a material difference to quality of life. The intelligence framework described in this paper provides the evidence base to identify where these interventions are most needed and to make the case for investing in them. The ambition is not simply to document suffering, but to create the conditions in which it can be prevented, recognised and addressed.

# Chapter 1
## Understanding the Challenge

### The Success of Radiotherapy

Radiotherapy is one of the most important tools in cancer medicine. It is used in the treatment of a wide range of cancer types — including breast, prostate, colorectal, cervical, bladder, endometrial, anal and lung cancers — and it plays a role in the treatment of approximately half of all cancer patients at some point in their care. Its effectiveness in achieving local tumour control, reducing the risk of recurrence and improving overall survival is well supported by evidence, and continued innovation in radiotherapy techniques has made it possible to deliver increasingly precise treatment with reduced exposure to surrounding healthy tissue.

Historically, the success of radiotherapy was measured primarily in terms of survival, tumour control and treatment completion. These measures remain critically important, and the continued improvement in cancer outcomes that radiotherapy has contributed to is one of the most significant achievements in modern healthcare. For many patients, radiotherapy represents the treatment that makes long-term survival possible.

### The Long Shadow of Treatment

The biological effects of radiotherapy do not end when treatment ends. Radiotherapy works by delivering targeted doses of ionising radiation that damage the DNA of cancer cells and prevent their reproduction. In achieving this effect, radiotherapy inevitably also affects healthy tissue in and around the treatment field. For many patients, this produces acute effects during and immediately after treatment. For a significant proportion, it also produces late effects — consequences that emerge gradually in the months and years following treatment, as the cumulative impact of radiation exposure on tissues and organs becomes apparent.

Late effects of radiotherapy are diverse and can affect almost any organ system, depending on the anatomical location treated. For patients who have received pelvic radiotherapy — which encompasses colorectal, prostate, cervical, endometrial, bladder and anal cancers — the consequences can include chronic bowel dysfunction, bladder dysfunction, sexual health consequences, lymphoedema, hip and pelvic bone changes, and peripheral neuropathy. In all cases, the experience of late effects can be profoundly disruptive to quality of life, independence and social functioning.

### The Scale of the Problem

Evidence-informed estimation models suggest that the scale of LER in any given NHS Trust may be considerably larger than previously recognised. For pelvic radiotherapy-treated cancer types, estimated rates of any late effects range from approximately 32% for prostate

cancer to approximately 60% for anal cancer, with rates of severe late effects ranging from approximately 7% to 18% across cancer types. These figures, applied to the patient volumes within any NHS Trust, produce estimates of LER burden with significant implications for service planning, workforce development and commissioning.

It is important to note that these estimates are planning midpoints informed by published evidence, not precise prevalence statistics. They are subject to uncertainty and should be used for service planning and prioritisation rather than as exact claims about the number of patients affected. Nevertheless, even at the lower bounds of plausible estimates, the likely scale of unaddressed late effects burden in most NHS Trusts is substantial and warrants serious attention.

## The Breadth of Late Effects Experience

The experience of late effects of radiotherapy extends across every dimension of survivorship. Physically, patients may contend with bowel urgency, incontinence or obstruction; urinary frequency, urgency or incontinence; sexual dysfunction; chronic pelvic or abdominal pain; fatigue; and reduced mobility. These physical consequences can be debilitating, embarrassing and socially isolating. Many patients report that they did not receive adequate information about the risk of late effects before their treatment, and that they did not know where to turn when symptoms developed.

Emotionally, the experience of late effects can compound the psychological burden of cancer itself. Patients who develop significant bowel or bladder symptoms after treatment may experience shame, anxiety and reduced self-confidence. Those who experience sexual health consequences may struggle with the impact on intimate relationships and personal identity. Fear that symptoms may indicate cancer recurrence is common and may lead to repeated health-seeking behaviour or avoidance of medical contact. The emotional dimension of late effects is frequently underrecognised in clinical settings.

Functionally, late effects can significantly impair the ability to work, to perform daily activities, and to maintain social and community participation. Patients who experience significant bowel or bladder dysfunction may find sustained employment impossible; those with fatigue and pain may struggle with the physical demands of daily life. These functional consequences carry economic implications — for the individual, for employers and for the welfare and social care system — that are rarely factored into assessments of the true cost of cancer treatment.

# Chapter 2
## Why Existing Intelligence Is Not Enough

### What Existing Systems Capture

The cancer intelligence infrastructure available to NHS organisations is substantial and, in relation to its primary objectives, effective. Cancer registration data provides comprehensive information about cancer incidence across tumour types, geographies and patient populations. Radiotherapy datasets record the delivery of radiotherapy treatment, including the dose delivered, the fractions used and the anatomical sites treated. Waiting times and treatment activity data provide insight into the speed and volume of radiotherapy pathways. Clinical outcome data, including survival and recurrence statistics, provides a measure of radiotherapy's effectiveness at its primary objective. These datasets are valuable and their continued development is important.

What they do not capture — systematically, at scale and in a form usable for service planning — is what happens to patients after their radiotherapy treatment is complete. There is no routine national dataset that records the development of late effects in radiotherapy-treated patients. There is no systematic process for identifying which patients are experiencing late effects, how severe those effects are, or what support they are receiving. The experience of living with the consequences of radiotherapy is, in the current intelligence environment, largely invisible.

### The Visibility Problem

This invisibility reflects a deeper structural feature of how cancer services have historically been organised. Cancer services have been built around the treatment episode. When that episode concludes, the patient typically moves out of the acute cancer care system into a follow-up arrangement that may not be well configured to identify and respond to late effects. For many patients, the follow-up pathway does not include systematic assessment for late effects, and general practitioners — who often become the primary point of contact after treatment — may not have the specialist knowledge needed to recognise late effects or to refer patients appropriately.

The result is that late effects often remain undiagnosed and unsupported for extended periods. Patients may attribute their symptoms to ageing or to other conditions, rather than recognising them as treatment consequences for which support may be available. And commissioners and service planners, lacking the intelligence to understand the scale of the problem, may not prioritise investment in late effects services.

### The Need for a Different Kind of Intelligence

Addressing the late effects challenge requires intelligence that starts with the patient's experience rather than the system's processes. It requires systematic, population-level data about how radiotherapy-treated cancer survivors are living, which symptoms they are experiencing, and how severe the impact on their quality of life has been. The National Cancer Quality of Life Survey is the most significant available source of this kind of intelligence. Used alongside evidence-informed estimation models and cancer prevalence data, it provides a basis for identifying where LER burden may be greatest and where service development investment is most warranted.

# Chapter 3
## Available Intelligence Sources

### The National Cancer Quality of Life Survey

The National Cancer Quality of Life Survey (CQOLS) is the principal dataset underpinning this intelligence framework. Administered to cancer survivors at defined points following the completion of their initial treatment, CQOLS collects patient-reported outcomes across a range of dimensions directly relevant to quality of life and survivorship. It uses two complementary measurement instruments — the EQ-5D and the EORTC QLQ-C30 — to provide a comprehensive picture of how cancer survivors are living after treatment. As the only national dataset that systematically captures patient-reported outcomes for cancer survivors at scale, CQOLS is a uniquely valuable source of intelligence for understanding the lived experience of radiotherapy-treated patients.

### EQ-5D and the Visual Analogue Scale

The EQ-5D is a standardised instrument for measuring health-related quality of life across five dimensions: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. For each dimension, respondents indicate the level of difficulty they are experiencing, producing a profile of health status that can be compared across populations and over time. The Visual Analogue Scale, administered alongside the EQ-5D, provides a single overall self-reported health status score on a scale from zero to one hundred. Together, these measures provide a robust and internationally validated picture of health-related quality of life that can be aggregated to the level of NHS Trust, cancer type and patient group, enabling meaningful comparison against national benchmarks.

### EORTC QLQ-C30

The EORTC QLQ-C30 is a cancer-specific quality of life questionnaire that captures a broader range of dimensions than the EQ-5D, including physical functioning, emotional functioning, social functioning, cognitive functioning, role functioning, fatigue, pain and a range of other symptom indicators. Its cancer specificity makes it particularly valuable for understanding the consequences of radiotherapy treatment. Several of the domains captured by the QLQ-C30 — particularly fatigue, pain, physical functioning and social functioning — are directly relevant to the late effects of radiotherapy and provide signals that warrant investigation at organisational and system level.

### Evidence-Informed LER Estimation Models

A key analytical development within the LER Intelligence Programme is the creation of evidence-informed estimation models that translate patient volume data and cancer-type-

specific incidence assumptions into approximate burden estimates at Trust, Cancer Alliance and ICB level. These models draw on published evidence from UK survivorship guidance and the systematic review literature on pelvic radiotherapy toxicity to establish midpoint assumptions for the proportion of treated patients likely to experience any late effects and severe late effects respectively. Applied to patient volume data from the CQOLS national invite dataset, these models produce trust-level estimates of likely LER burden that can support service planning and investment decisions.

Current model assumptions suggest the following approximate rates of late effects for the major pelvic radiotherapy cancer types: prostate (32% any, 7% severe), colorectal and rectal (47% any, 14% severe), bladder (45% any, 11% severe), cervix (55% any, 15% severe), endometrium (40% any, 8% severe) and anal cancer (60% any, 18% severe). These figures are planning midpoints rather than precise prevalence statistics and should be used accordingly.

## Cancer Prevalence and Supporting Datasets

Cancer prevalence data provides the population context within which CQOLS and estimation model outputs should be interpreted. Understanding the size and composition of the radiotherapy-treated survivorship population within a given organisation or geography is essential for contextualising quality of life findings and for understanding the absolute scale of likely LER burden. Patient experience datasets, including Care Opinion and SIA EQ-5D Plus surveys, offer complementary perspectives on the patient experience of cancer services that can enrich the overall intelligence picture.

# Chapter 4
## The Contribution of CQOLS to LER Intelligence

### From Treatment Records to Lived Experience

The fundamental value of CQOLS to the LER intelligence framework lies in what it measures. Radiotherapy datasets tell us about the treatment that was delivered. Clinical outcome data tells us about survival and recurrence. Neither tells us how patients are experiencing their lives in the years after treatment ends — what symptoms they are living with, how severely those symptoms affect their daily functioning, and where the greatest unmet needs lie. CQOLS, by contrast, starts with the patient and captures their experience directly. It makes visible what has previously been invisible: the lived reality of survivorship for people who have been treated with radiotherapy.

This does not mean that CQOLS can diagnose late effects or definitively attribute patient-reported symptoms to radiotherapy specifically. CQOLS is not a clinical assessment tool and should not be used as one. What it can do is identify, at population level, the domains in which radiotherapy-treated cancer survivors are reporting the greatest difficulties, and where those difficulties are concentrated — by cancer type, by organisation, by geography and by patient group. This intelligence is sufficient to prompt the right clinical and organisational conversations, to identify where further investigation is warranted, and to prioritise the development of services and pathways.

### Domains Most Relevant to Late Effects

Several of the domains captured by CQOLS are directly relevant to the kinds of difficulties most commonly associated with late effects of radiotherapy. Physical functioning — the ability to manage daily activities, maintain independence and engage in physical tasks — is frequently affected in patients who have experienced significant late effects. Pain and symptom burden is among the most commonly reported consequences of pelvic radiotherapy late effects. Fatigue — persistent, debilitating tiredness that is not relieved by rest — is another hallmark of late effects experience and is systematically captured within the QLQ-C30. Social functioning and role functioning may be significantly impaired where physical late effects are severe. Emotional wellbeing, including anxiety and depression, frequently accompanies the physical dimensions of late effects and warrants independent attention.

### From Estimated Burden to Estimated Need

One of the most important analytical developments within the LER framework is the linkage of CQOLS patient-reported outcomes with the evidence-informed estimation model to move from estimated burden to estimated support need. Where an NHS Trust has a substantial estimated LER burden — based on patient volumes and cancer-type-specific incidence

assumptions — and where CQOLS data for that Trust also shows elevated rates of reported difficulty in domains consistent with late effects, the combination of these two intelligence sources provides a compelling basis for service planning action. Future development within the programme will focus on operationalising this linkage, creating an integrated intelligence product that organisations can readily use for planning and commissioning decisions.

# Chapter 5
## What the Intelligence May Be Telling Us

### Patterns of Unmet Need

Analysis of CQOLS data for radiotherapy-treated cancer populations reveals patterns of reported difficulty that are consistent with the known profile of late effects. Across cancer types associated with pelvic radiotherapy, elevated rates of reported difficulty with physical functioning, pain, fatigue and social participation are detectable within CQOLS data, and these rates vary — sometimes substantially — between NHS organisations. Some Trusts show radiotherapy-treated patient populations reporting difficulty in these domains at rates significantly above the national comparator; others show relatively lower rates of reported difficulty. These patterns are consistent with differential late effects burden and warrant clinical investigation.

### Cancer Type and Symptom Domain

The relationship between cancer type and the domains in which patients report greatest difficulty is an important analytical dimension of the LER intelligence framework. Patients treated for colorectal, cervical or anal cancer with pelvic radiotherapy may show particularly elevated rates of bowel-related difficulty, while prostate cancer patients may show more pronounced genitourinary symptoms. Gynaecological cancer patients may report elevated rates of difficulty across multiple domains, reflecting the combination of pelvic radiotherapy with surgery and systemic treatment. Understanding these cancer-type-specific patterns enables organisations to configure their late effects assessment and support services in ways that are appropriately matched to the likely profile of need within their patient populations.

### The Signal and What It Prompts

The purpose of identifying these patterns is not to establish definitive conclusions about the cause of patient-reported difficulties. CQOLS data alone cannot distinguish late effects of radiotherapy from other post-treatment consequences or from the effects of comorbidities. What it can do is identify where the burden of reported difficulty is unexpectedly high and where clinical teams should look more carefully. Where a Trust's radiotherapy-treated patients are reporting pain, fatigue or functional limitation at rates significantly above the national comparator, this is a signal that deserves investigation: is there a specific treatment pathway or patient group driving the pattern? Are late effects being systematically assessed and managed? Are appropriate specialist services available to the patients who need them? These are the questions that CQOLS intelligence can prompt, and they are the questions from which service improvement begins.

# Chapter 6
## Service Improvement Opportunities

### Late Effects Clinics and Specialist Assessment

The most significant gap in late effects service provision in many NHS organisations is the absence of dedicated late effects assessment and management pathways. Specialist late effects clinics — staffed by clinicians with expertise in the recognition, investigation and management of radiotherapy consequences — can provide a systematic approach to identifying patients with late effects, investigating the underlying causes and mechanisms, and developing management plans tailored to individual patients' needs and circumstances. Where CQOLS data and estimation models suggest a substantial late effects burden within a Trust's patient population, the case for investing in specialist late effects clinic capacity is strong, and the intelligence available through this framework provides a basis for making that case to clinical and organisational leadership.

### Pelvic Health Rehabilitation

For the large proportion of late effects patients whose difficulties relate to pelvic organ dysfunction — bowel, bladder and sexual health consequences — pelvic health physiotherapy and rehabilitation represents one of the most effective and evidence-based interventions available. Specialist pelvic health physiotherapists can assess and treat a range of symptoms associated with pelvic radiotherapy late effects, including bowel urgency and incontinence, urinary dysfunction and pelvic floor impairment. Access to these services remains variable across England, and where CQOLS data shows elevated rates of independence and daily living difficulties in pelvic cancer populations, a structured assessment of pelvic health rehabilitation pathway availability and capacity is an appropriate and practical response.

### Psychological Support

The emotional consequences of late effects are frequently underestimated in service planning, yet they are real, significant and often compounding. Patients who experience chronic bowel or bladder symptoms may develop anxiety, depression and social withdrawal that are as debilitating as the physical symptoms themselves. Patients whose sexual health has been affected may experience profound impacts on their relationships and sense of self. The fear that ongoing symptoms represent cancer recurrence is common and requires sensitive clinical management. Where CQOLS data identifies elevated rates of emotional difficulty in radiotherapy-treated patient populations, this creates a clear basis for reviewing the availability and accessibility of psychological support — including specialist cancer psychology, community mental health provision, peer support and guided self-help.

## Personalised Follow-Up and Holistic Needs Assessment

The systematic identification of late effects within radiotherapy-treated patient populations requires a follow-up model that is sensitive to the possibility of late effects and configured to detect them when they develop. Holistic needs assessment, delivered consistently to radiotherapy-treated patients at appropriate intervals after treatment completion, provides a structured mechanism for identifying both physical and emotional late effects needs and for connecting patients with the support services that can address them. Treatment summaries that clearly communicate the radiotherapy received, the tissues exposed and the potential late effects that may emerge are an important tool for ensuring that patients, GPs and other clinicians can recognise late effects when they develop.

## Patient Education and Self-Management

Empowering patients to understand and manage their own late effects experience is an important complement to specialist clinical services. Many late effects can be partially managed through self-care strategies — dietary modification for bowel symptoms, pelvic floor exercises for urinary dysfunction, fatigue management techniques for persistent tiredness. Where patients understand what late effects are, what symptoms to look out for and when to seek help, they are better placed to advocate for themselves within the healthcare system and to engage productively with the specialist services that exist.

## Living With and Beyond Cancer Programmes

The broader Living With and Beyond Cancer (LWBC) infrastructure — including health and wellbeing events, supported self-management programmes and community-based support — provides an important context for late effects support. Integrating late effects assessment and management within the wider LWBC pathway ensures that patients who have received radiotherapy are systematically considered within survivorship planning, and that the specific nature of late effects is recognised as a distinct and clinically important dimension of cancer survivorship.

# Chapter 7
## Health Economics Considerations

### The Burden of Unmanaged Late Effects

The health and care system costs associated with unmanaged late effects of radiotherapy are substantial, though they are distributed across multiple care settings and over extended time periods in ways that make them difficult to measure directly. Patients with chronic bowel or bladder dysfunction may generate repeated primary care consultations over many years, seeking management of symptoms that are never attributed to their radiotherapy or addressed through specialist pathways. Those with severe fatigue or pain may require multiple outpatient appointments, investigations and medication trials before an effective management plan is established. Emergency hospital presentations related to bowel obstruction, urinary tract complications or other radiotherapy sequelae may occur in patients who have never been assessed for late effects. The cumulative cost of these avoidable or sub-optimally managed healthcare contacts represents a significant and poorly quantified burden on NHS resources.

### The Hidden Costs of Inaction

Beyond direct healthcare costs, the consequences of unmanaged late effects extend to the wider economy and to social care systems. Patients who experience significant bowel, bladder or pain-related late effects may be unable to sustain employment, creating costs for individuals, employers and the benefits system. Those who lose independence as a result of late effects may require social care or informal carer support that would not have been needed had effective late effects management been available. The psychological consequences of unaddressed late effects — anxiety, depression, social withdrawal — may generate demand for mental health services that could have been avoided through earlier identification and support.

The economic case for investing in late effects services is therefore not simply about reducing NHS expenditure, though there is likely to be a meaningful return on investment from better-managed late effects in terms of reduced primary and secondary care utilisation. It is also about the broader social and economic value of maintaining the health, independence and quality of life of the growing population of radiotherapy-treated cancer survivors.

### The Return on Investment in Late Effects Services

The evidence base for the economic return on investment in late effects services is still developing, but the available evidence is encouraging. Specialist pelvic health physiotherapy has been shown to be effective in managing bowel and bladder symptoms associated with pelvic radiotherapy, and the cost of delivering such services is modest relative to the sustained healthcare utilisation that unmanaged pelvic dysfunction can generate.

Psychological support for cancer survivors has been shown to reduce emergency presentations and improve self-management. Structured late effects assessment pathways that identify and address needs proactively are likely to be more cost-effective than reactive management of escalated complications.

## Future Evaluation Opportunities

The LER Intelligence Framework creates the conditions for a more rigorous evaluation of late effects burden and its consequences than has previously been possible. By tracking patient-reported outcomes over time, by linking CQOLS data with healthcare utilisation datasets, and by monitoring the impact of service changes on patient-reported quality of life, it becomes possible to generate the evidence needed to make a robust economic case for late effects investment. Future work should include formal modelling of the relationship between LER burden estimates and actual healthcare utilisation, evaluation of the impact of specific interventions on patient-reported outcomes, and longitudinal analysis of how late effects burden evolves over the years following radiotherapy treatment.

# Chapter 8
## Strategic Questions for Stakeholders

### The Purpose of These Questions

This paper is designed to stimulate discussion rather than prescribe conclusions. The LER Intelligence Framework will be most effective when the intelligence it provides is interrogated, validated and interpreted in the context of local clinical knowledge, patient feedback and organisational priorities. The questions that follow are intended as a starting point for that discussion — prompts for the kind of reflective, evidence-informed dialogue from which genuine service improvement can emerge.

### Identifying Late Effects in Current Practice

Organisations engaging with LER intelligence should begin by examining how, if at all, late effects of radiotherapy are currently being identified within their patient populations. Is there a systematic process for assessing patients for late effects at defined intervals after treatment? Are treatment summaries routinely shared with patients and GPs, and do they include information about the potential for late effects? Are clinicians in general practice and community settings able to recognise late effects when patients present with relevant symptoms, and do they know how and where to refer? The answers to these questions will help to establish the baseline from which improvement can be measured.

### Service Availability and Configuration

A second area for discussion is the current configuration of late effects services within the organisation and across the wider system. What specialist services currently exist for patients with late effects of radiotherapy — late effects clinics, pelvic health physiotherapy, bowel rehabilitation, psychological support? Are these services accessible to patients across the cancer types most likely to be affected? Are there waiting times or referral barriers that prevent patients from receiving the support they need? How well are late effects services integrated with the broader Living With and Beyond Cancer pathway? Understanding the current service landscape is essential for identifying where investment and development are most needed.

### Using Intelligence More Effectively

Organisations should reflect on how the LER intelligence available through this framework can be most effectively used. CQOLS data, estimation model outputs and cancer prevalence data should be brought together to create a coherent picture of likely LER burden and patient-reported need within the organisation. This picture should inform clinical discussions — within tumour groups, between clinical nurse specialists and radiotherapy teams, and in

conversations with LWBC leads and personalised care teams. It should also inform commissioning and planning discussions, providing the evidence base for investment cases and service development proposals.

## Evidence Gaps and Research Opportunities

Finally, stakeholders should consider where the evidence gaps are greatest and what contribution their organisation might make to addressing them. The evidence base for late effects of radiotherapy, while substantial, is uneven across cancer types and treatment modalities, and the evidence for the effectiveness of specific interventions is in many areas limited. Organisations with relevant patient populations, clinical expertise and analytical capacity have an opportunity to contribute to the development of this evidence base through audit, service evaluation and formal research.

# Chapter 9
## Conclusions

### Radiotherapy's Success Creates a New Responsibility

Radiotherapy has played a transformative role in improving cancer survival across England. It has given life to hundreds of thousands of patients who would not otherwise have survived their cancer, and its importance to cancer medicine will only grow as treatment techniques continue to advance. This success is profound and deserves recognition. It also creates a responsibility that has not yet been fully discharged: the responsibility to understand, acknowledge and address the long-term consequences that radiotherapy inflicts on the people it saves.

Late effects of radiotherapy are not a marginal or rare problem. Evidence from published literature and evidence-informed estimation models suggests that a substantial proportion of radiotherapy-treated cancer survivors — particularly those who received pelvic radiotherapy — live for years with physical, emotional and functional consequences that are directly attributable to their treatment. For many of these patients, those consequences remain unrecognised, uninvestigated and unsupported. The scale of the unmet need is large, and the gap between what patients are experiencing and what the NHS is currently equipped to address is real and significant.

### What CQOLS Reveals About Late Effects Burden

The National Cancer Quality of Life Survey provides a window into this hidden burden that no other national dataset currently offers. By capturing patient-reported outcomes directly from cancer survivors, CQOLS makes visible the domains in which patients are experiencing the greatest difficulties: physical functioning, pain, fatigue, emotional wellbeing and social participation. These are precisely the domains in which late effects of radiotherapy characteristically manifest. While CQOLS cannot diagnose late effects or attribute symptoms definitively to radiotherapy, it can identify where the burden of reported difficulty is concentrated — by cancer type, by NHS organisation, by geography — and where clinical investigation and service development are most urgently warranted.

When CQOLS patient-reported outcomes are combined with evidence-informed estimation models that translate patient volume data into approximate LER burden estimates, the result is an intelligence framework of real practical value. Organisations can develop a structured view of the likely scale of late effects burden within their patient populations, compare patient-reported quality of life against national benchmarks, and identify where the signals of unmet need are strongest. This intelligence provides a defensible and evidence-based foundation for clinical discussion, service planning and investment decisions.

## Intelligence at Every Level of the System

One of the most significant features of the LER Intelligence Framework is its ability to operate simultaneously at multiple levels of the healthcare system. At NHS Trust level, CQOLS data and estimation model outputs can be used to identify which cancer types are generating the greatest late effects burden, which domains of quality of life are most affected, and where clinical teams should focus their attention. At Cancer Alliance level, system-wide patterns can be identified — revealing whether late effects burden is concentrated in particular organisations or geographies, and informing the case for coordinated system-level service development. At Integrated Care Board level, the intelligence can support population health planning, informing commissioning decisions about late effects services and helping to ensure that resources are directed where need is greatest.

## From Signal to Action

Intelligence about late effects burden is valuable only insofar as it leads to action. The pathway from signal to action requires clinical teams to engage with the evidence, to validate it against their own knowledge and experience, and to translate it into practical service decisions. Where CQOLS data and estimation models identify a concentration of late effects burden, organisations should ask: are we systematically assessing our patients for late effects? Do we have the specialist services needed to manage what we find? Are our follow-up pathways configured to identify late effects when they develop? Are we providing adequate psychological support for the emotional consequences of late effects? And what changes — to pathways, services, referral arrangements, patient education — would reduce the burden that our patients are currently carrying unsupported?

The LER Intelligence Framework is not a performance management tool and it does not seek to judge organisations. Its purpose is to illuminate — to make visible a problem that has been hidden — and to create the conditions in which constructive clinical and organisational conversations can happen. Those conversations, grounded in patient-reported evidence, are the mechanism through which the commitment of NHS organisations to their patients' wellbeing is translated into better care.

## The Health Economics Case

The costs of unmanaged late effects of radiotherapy are distributed across multiple care settings, extended over many years, and rarely attributed to their underlying cause. Repeated primary care consultations for symptoms that are never identified as late effects; emergency presentations for complications that could have been prevented or managed in specialist services; loss of employment and independence; mental health service utilisation driven by the emotional burden of unaddressed physical symptoms — these costs accumulate over time and represent a significant and avoidable burden on the NHS and the wider economy. Investing in late effects assessment and management is likely to generate meaningful returns in terms of reduced downstream service demand and sustained independence and quality of life for patients.

## Translating Intelligence into Better Lives

The ultimate measure of the LER Intelligence Framework is whether it improves the lives of people living with the consequences of radiotherapy. The intelligence available through CQOLS and the estimation models provides the foundation; the impact depends on what NHS organisations choose to do with it. Where Trusts use LER intelligence to initiate clinical discussion and implement practical service changes, patients will receive better and more appropriate support for their late effects. Where Cancer Alliances use system-level intelligence to commission coordinated late effects pathways, the benefits will reach more patients more consistently. Where ICBs incorporate LER intelligence into their population health planning, the commissioning decisions that follow will better reflect the real needs of radiotherapy-treated cancer survivors.

The ambition is not modest: to ensure that every person who survives cancer because of radiotherapy receives the support they need to live well with its consequences. That ambition will not be achieved quickly or easily. But the intelligence described in this framework makes it possible to begin — to understand the scale of the challenge, to identify where the greatest needs lie, and to take the first practical steps towards addressing them.

## Looking Forward

The LER Intelligence Programme is at an early stage of development. The analytical tools, datasets and service intelligence it brings together represent a significant step forward, but there is much more to be done. The evidence base for late effects of radiotherapy needs to continue to develop. The linkage between CQOLS patient-reported outcomes and LER estimation models needs to be operationalised and made routinely accessible to organisations at Trust, Alliance and ICB level. And the service landscape for late effects — currently fragmented, inconsistently available and under-resourced in most parts of England — needs to be developed and strengthened in ways that reflect the scale and urgency of the challenge.

None of this can happen without the engagement and commitment of the clinical teams, service leaders, commissioners and patients who are closest to the problem. This paper is an invitation to that engagement. The evidence of need is clear. The intelligence tools to understand it more precisely are available or in development. What is needed now is the will to act — to use the intelligence that exists, to build the services that patients require, and to ensure that the success of radiotherapy in treating cancer is matched by an equally serious commitment to supporting the people who live with its consequences.

## Conclusion

The success of radiotherapy in improving cancer survival creates a growing and inescapable responsibility to understand and address its long-term consequences. Late effects of radiotherapy are common, often severe and, in many cases, amenable to intervention. The intelligence available through the National Cancer Quality of Life Survey and evidence-informed estimation models provides, for the first time, a practical basis for identifying where that burden is greatest and for making the case for investment in the services and pathways that can address it. The opportunity now is for NHS organisations at every level to use this intelligence — to look honestly at what the data is telling them about the patients they have

treated, to have the clinical and organisational conversations that the evidence warrants, and to build the late effects services that cancer survivors deserve.