NHS
South, Central and West
Commissioning Support Unit

NHS
Somerset, Wiltshire,
Avon and Gloucestershire
Cancer Alliance

Evaluation- Southwest Radiotherapy Late Effects Services.

Somerset, Wiltshire, Avon & Gloucestershire Cancer Alliance

Contents

Forward by Macmillan

‘It has been a privilege for Macmillan to invest in and support this project, the first of its kind in the UK, whereby all the NHS trusts in SWAG cancer alliance have worked with Macmillan to give all patients across the Southwest region the same level of support.

As cancer treatments improve so do cancer survival rates, however whilst this is excellent news, we know this is not the full story and Macmillan estimate around 1 in 4 people with cancer are living with the long-term effects of cancer or its treatment. These effects can often have a life changing impact for individuals and dramatically impact their quality of life. It has always been important to Macmillan that people affected by cancer receive high quality care and support to enable them to live well after cancer, as we move forward, we want to reduce variation in treatment and care through our partnerships and system transformation. There is no greater example of this than the Southwest Late effects services.

We also know how integral the cancer workforce is in improving outcomes for cancer patients. Working together, sharing best practice, supporting a team development approach has further enhanced patient care as well as the education and development of the wider workforce. A model which supports the retention not only of the highly skilled practitioners in the team who have become an asset to their respective organisations but has impacted further afield providing support to new services in other regions. Sharing best practice at a local, national, and international level was one of the many reasons highlighted by the judges in awarding the team the Innovation award at the Macmillan Professional Excellence Awards.

The team and those who support them should be immensely proud of what they have achieved for the people of the Southwest in such a short period of time.’

Kate Williams
Strategic Engagement and Improvement Manager - South.

MACMILLAN.
CANCER SUPPORT

1. Executive Summary

This report provides details of the independent evaluation of the Radiotherapy Late Effects Services across the geography of Somerset, Wiltshire, Avon, and Gloucestershire (SWAG) Cancer Alliance.

The NHS Long Term Plan[1] outlines the ambition that by 2028, the proportion of cancers diagnosed in the early stages (1 and 2) will rise from 50% to 75%. Achieving this target will result in 55,000 more people each year surviving cancer for at least five years post-diagnosis. Whilst survival rates are increasing; conservative estimates suggest that 50% of cancer patients experience one or more adverse effect post treatment.[2]

Radiotherapy-related late effects pose a significant challenge for cancer survivors, often resulting in long-term physical and emotional difficulties that impact their quality of life. Due to a lack of specialist services locally, patients identified with radiotherapy late effects often must attend multiple GP and secondary care appointments to identify the cause of their symptoms. Some patients with severe symptoms will require attendance at specialist services significant distances from their homes. Symptoms may include bowel and bladder incontinence which can make travel to these centres difficult and distressing for patients. The Southwest Radiotherapy Late Effects Services (SWRLES) funded by Macmillan Cancer Support and supported by the SWAG Cancer Alliance, plays a crucial role in improving health outcomes for cancer survivors by delivering specialised, local, person-centred care for managing radiotherapy-related complications.

SWAG commissioned NHS South Central and West Commissioning Support Unit (SCW) to conduct this evaluation to analyse the effectiveness, efficiency, and experience of the SWRLES to support commissioning intentions and inform individual Trust business planning. The SWRLES steering group developed key performance indicators which were used to examine the following evaluation objectives:

[1] https://www.longtermplan.nhs.uk/
[2] https://www.england.nhs.uk/cancer/living/

Evaluation Objective	Evaluation Metric
Is a Radiotherapy Late Effects Service necessary and efficient?	• SWRLES usage data • Symptom reporting
Is a Regional Radiotherapy Late Effects Service Model effective?	• Healthcare activity and utilisation. • Patient-reported outcome measures (PROMS)
Do patients and service providers value a Radiotherapy Late Effects Service?	• Patient surveys • Patient focus groups • Staff satisfaction assessments

Key Evaluation Findings

From a healthcare utilisation perspective, data from the pre-existing Somerset Radiotherapy Late Effects Service (RLES) analysis demonstrates substantial cost avoidance. This includes a reduction in outpatient appointments, non-elective admissions, and Emergency Department (ED) visits.

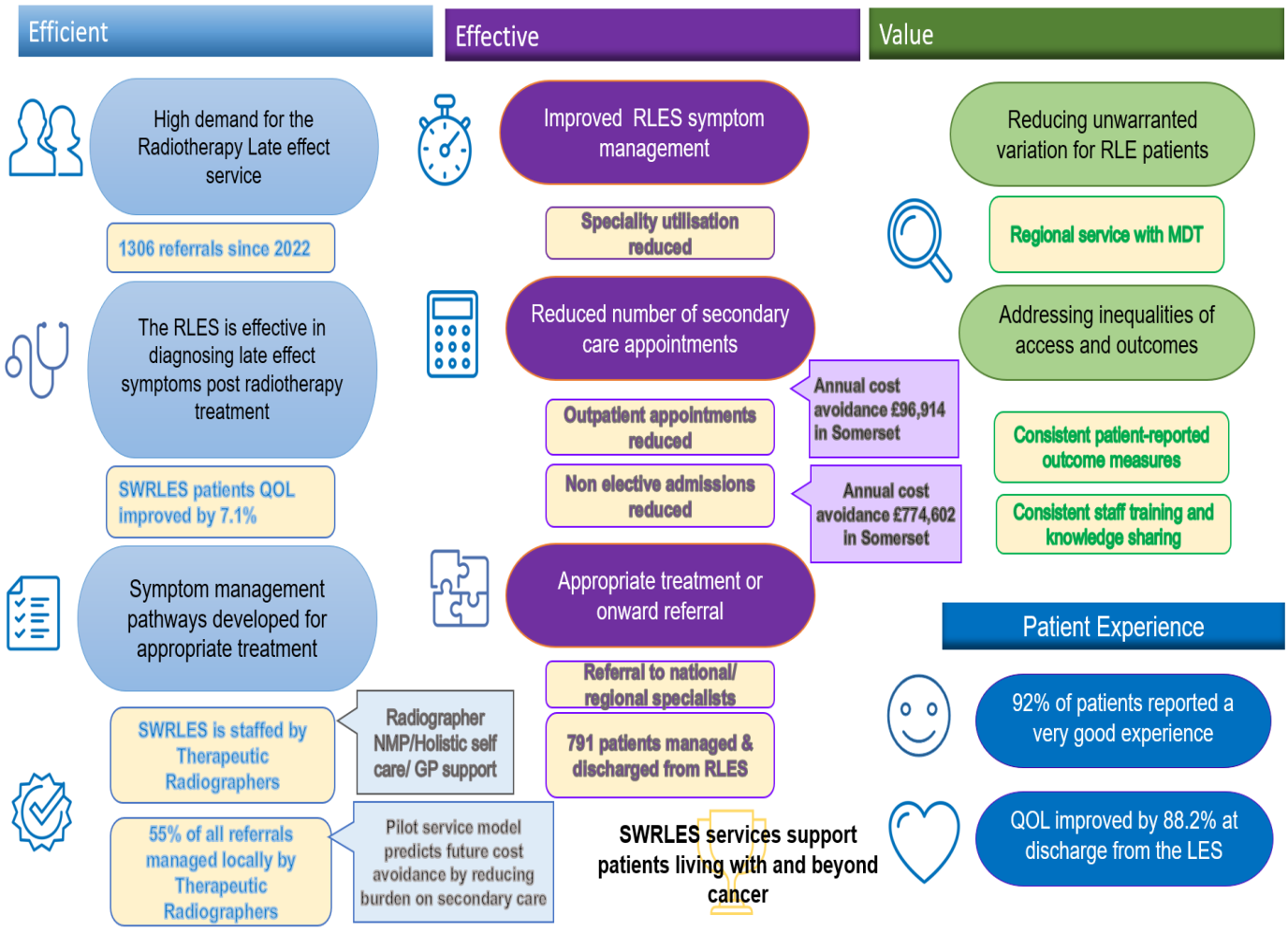
Prostate cancer patients alone experienced a reduction in outpatient appointments valued at £61,007 over the lifetime of the service, with £14,705 saved in its first year. Since its inception, the overall cost avoidance across multiple specialties has reached a potential of approximately £96,914, reflecting the financial benefits of early referral to RLES. Additionally, the service has demonstrated a reduction in non-elective hospital admissions, with estimated cost avoidance reaching £774,000 since its launch. In 2023, this figure increased by £190,000. Patients referred to RLES are demonstrably less likely to require unplanned hospital admissions compared to those with untreated late effects, once again reinforcing the importance of early intervention in managing long-term healthcare needs.

NOTE: This healthcare utilisation data only applies to Somerset data therefore the potential cost avoidance, when other areas have larger datasets to analyse, is substantially higher.

Evaluation of the services through the Quality-of-Life Survey (QOLS) and patient-reported outcome measures (PROMs), such as the EQ-5D-5L and EORTC QLQ-C30, indicates that while many patients experience improvements in quality-of-life following referral to SWRLES

some continue to face significant challenges. These tools have proven effective in measuring health-related quality of life and identifying areas for service enhancement. Furthermore, patient feedback highlights the necessity of personalised, face-to-face consultations and improved access to and education on managing late effects. This underscores the importance of enhanced interprofessional collaboration, and the critical expertise offered by Therapeutic Radiographers throughout the radiotherapy pathway. There is the potential to develop shared learning and reduce inequity across the region and ultimately offer aligned comparable late effects services across the country.

Infographic Summary of Radiotherapy Late Effects Services



Summary of Service Evaluation Findings

Value	Category	Measure	Evidence
Is a RLES necessary & efficient?	**Patient usage of Services**	• SWRLES patient numbers exceeded expectation over the pilot period demonstrating a healthcare burden.	• **1306** referrals since services started (2022) • Broad range of late effect symptoms reported
Is a RLES model effective?	**Improved Patient Outcomes/ Management**	• Patients have been discharged from the services demonstrating effective late effects management.	• **791** patients discharged from services since started (2022).
	Enhanced Quality of Life	• Positive patient-reported outcomes highlighting meaningful improvements in QoL.	• **88.2% patients reported an improvement in QoL**
	Financial	• Patients managed as defined by proposed service model. • Reduced utilisation of secondary care OP services.	• **55%** of patients managed by Therapeutic Radiographers • Potential OP cost avoidance of **£96,914** since started • Increase in clinic capacity and specialty utilisation
		• Decreased non-elective admissions	• **640** less NE-admissions resulting in potential cost avoidance of **£774,602** across all cancer types since started
		• Efficient redirection to appropriate and cost-effective services, such as physiotherapy.	• Breast surgery OP specialty usage significantly reduced; Physiotherapy service appropriately utilised
Do patients and service providers value a RLES?	**Patients**	• Encouraging, life changing survey and focus group feedback.	• **99%** patient feedback reported a positive impact from the services
	Staff	• Staff feedback; Potential for improved staff satisfaction, recruitment, and retention • Wider service feedback suggest burden is not being increased elsewhere.	• Wider service feedback suggests burden not being increased elsewhere • 51% of respondents from other services said their workload was reduced

Recommendations for Southwest Radiotherapy Late Effects Services (SWRLES)

The 2024 Lord Darzi Report, *Independent Investigation of the National Health Service in England*[3], evaluates the NHS and proposes reforms. The report emphasises the necessity for enhanced funding and a comprehensive national healthcare dialogue to sustain the effectiveness of the NHS.

In response, the 2025 Government have pledged a comprehensive 10-year reform plan to include:

- **Community and Preventive Care**
- **Digital Transformation**
- **Workforce Expansion**
- **Capital Investment**

Considering these ongoing changes in healthcare policy and infrastructure, it is essential that the SWRLES framework aligns with current and proposed healthcare reforms. The evaluation's recommendations consider these key factors.

SWRLES to be fully commissioned and supported by Trusts to be part of the permanent radiotherapy establishment
• **Continued investment in SWRLES is vital for equitable access, economic sustainability, and enhanced long-term care for cancer survivors.** • **Strengthening these services supports the NHS's vision for personalised, local cancer care, improving outcomes and quality of life for a growing cancer survivor population.** • **Crucially, it ensures ongoing, effective symptom management for existing patients within the services. Where would these patients be managed if no SWRLES?**

[3] https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england?

Explore elements of the SWRLES pathways that could move from hospitals to communities
• Enhancing pathways aligns with the government's vision for a future-ready NHS and treating patient closer to home and in the community. • Further analysis of local services could demonstrate how secondary care cost avoidance supports managing the rising cancer patient load. • This would optimise capacity benefits and improve patient outcomes on a broader scale.

SWRLES Utilisation of digital technology
There are potential opportunities to develop the SWRLES to utilise digital technologies: • Online surveys (PROMS, electronic Holistic Needs Assessments (eHNAs) • Automated data collection • Dashboards for improved analysis of service data and outcomes • Access to shared care records and Electronic Patient Record (EPR). • Access to primary care systems.

A permanent RLES would support prevention of ill-health (late effects)
• Enhancing awareness of radiotherapy late effects could facilitate earlier referrals to the RLES, preventing complications that may require costly regional or national services. • Emerging evidence should be explored to determine whether certain late effects can be mitigated through treatment adjustments or early RLES interventions. • Strengthening this evidence base would further demonstrate the RLES's value, and benefits both to patients and the healthcare system.

A permanent RLES would continue to share practice, utilise learning and develop national equitable services
• **Explore and develop how this award-winning, innovative service could serve as a cost-effective model for nationwide replication, ensuring equitable access to late effects care for all radiotherapy patients.**

Explore further analysis into SWRLES and economic impact on primary health care
• **Analysing primary care data remains challenging but would be a valuable area for future exploration.** • **Many patients have frequent GP appointments for issues linked to radiotherapy late effects.** • **Evaluating how earlier referral to an LES could reduce primary care utilisation and its financial impact would provide critical insights into further service efficiency and cost-effectiveness.**

The expansion of RLES across the Southwest represents a pioneering approach to addressing radiotherapy-related late effects. This model of care not only enhances patient outcomes but also reduces reliance on secondary and emergency care while demonstrating potential cost avoidance for the wider healthcare system. By addressing the unmet needs of adult cancer survivors, RLES aligns with broader NHS objectives of delivering personalised cancer care.

This evaluation provides compelling evidence to support the continued investment in SWRLES. It highlights that the SWRLES is cost-effective in healthcare resource management and provides a critical role in enhancing cancer survivors' quality of life. The data-driven insights from patient feedback and financial analysis underscore the service's value in improving patient care, reducing long-term healthcare burdens, and ensuring better outcomes for radiotherapy survivors. Sustained funding and development of a substantive SWRLES will be vital in achieving equitable access to these essential services, ultimately contributing to system-wide economic benefits.

2. Introduction

The aim of this independent service evaluation is to assess the impact of the Southwest Radiotherapy Late Effects services (SWRLES) and provide evidence to support economic sustainability once the current Macmillan funding ends in March 2025. This report presents a comprehensive analysis of both qualitative and quantitative data to address key questions regarding the need, effectiveness, and value of a Radiotherapy Late Effects Service:

Is a Radiotherapy Late Effects Service necessary and efficient?

- Assessed through fundamental SWRLES data.
- Patient symptom reporting.

Is a Regional Radiotherapy Late Effects Service Model effective?

- Evaluated financially based on healthcare activity and utilisation.
- Assessed through patient-reported outcome measures.

Do patients and service providers value the Radiotherapy Late Effects Services?

- Measured through patient surveys, focus groups.
- Staff satisfaction assessments.

This structured approach ensures a data-driven evaluation of services necessity, impact, and stakeholder value. More people than ever are living with and beyond cancer, due to the impact of early and faster diagnosis programmes and improved cancer treatment innovations.[4]The NHS Long Term Plan[5] outlines the ambition that by 2028, the proportion of cancers diagnosed in the early stages (1 and 2) will rise from 50% to 75%. Achieving this target will result in 55,000 more people each year surviving cancer for at least five years post-diagnosis. However, conservative estimates suggest that 50% of cancer patients experience one or more adverse effect post treatment.[6] This data does not include legacy cancer survivors already living with

[4] https://www.england.nhs.uk/cancer/living/
[5] https://www.longtermplan.nhs.uk/
[6] https://www.england.nhs.uk/cancer/living/

the long-term and late effects of their treatment, so the true impact of cancer treatment adverse effects is much higher.

Figure 1: Years since first diagnosis of patients LWBC[7] (National Data)

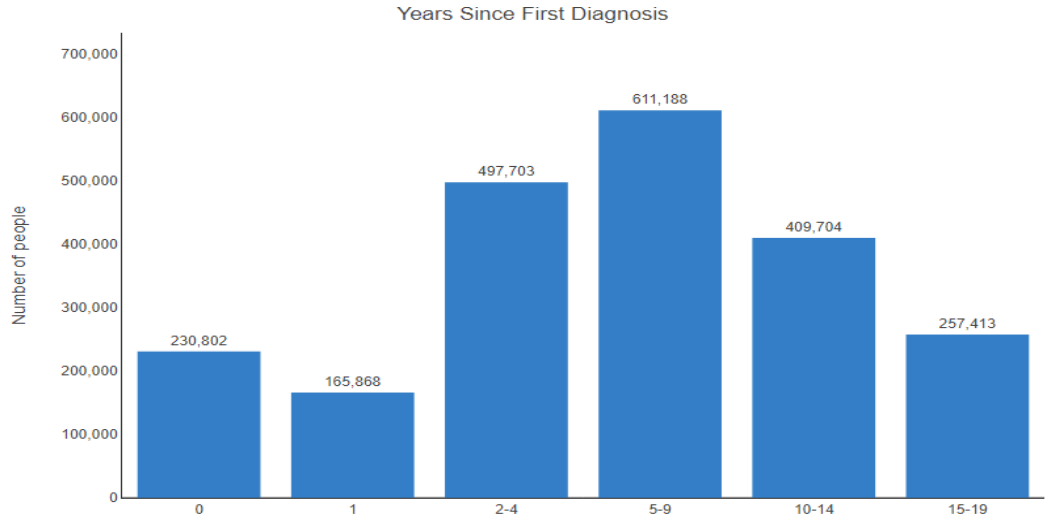
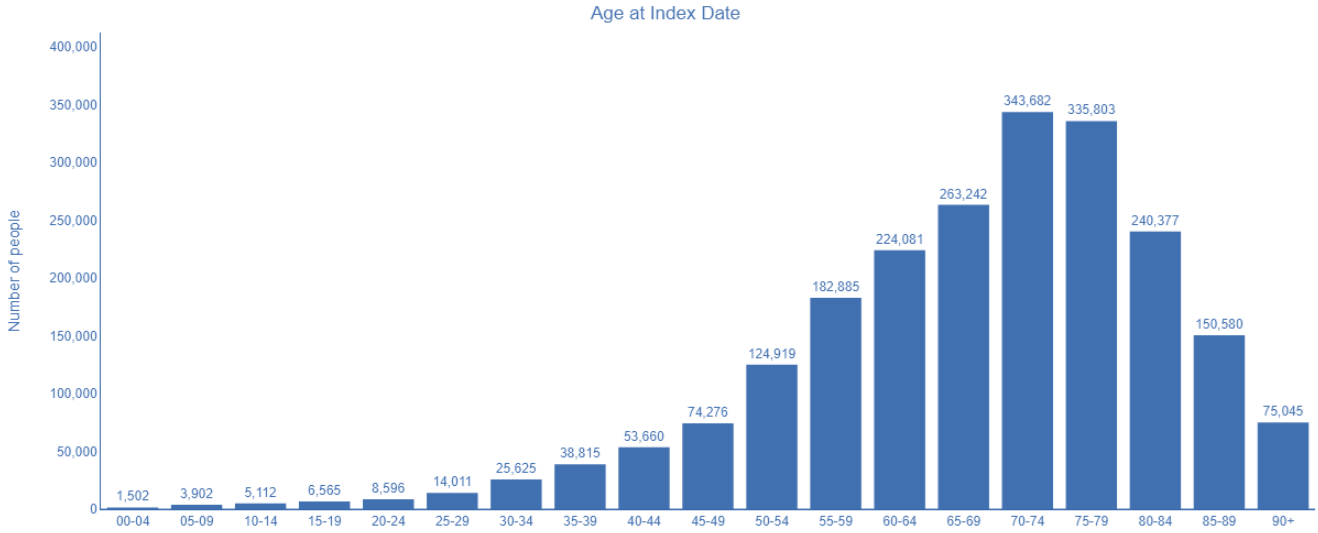


Figure 2: Total numbers of people LWBC 2002-2021 (National Data)



In 2013, Macmillan published the "Throwing Light on the Consequences of Cancer and its Treatment" report[8], which highlighted the significant post-treatment side effects. Many of these side-effects present sometime after completion of treatment and it can be difficult for

[7] Source 2024 Cancer Prevalence
[8] Macmillan 2013 Throwing light on the consequences of cancer

patients to access timely and appropriate assessment and management.

Radiotherapy is an essential component of the treatment of cancer, with half of all cancer patients requiring radiotherapy at some time during their illness. Late effects after radiotherapy can manifest months or even decades after treatment. The long-term side effects of radiotherapy treatment can be extremely debilitating for patients causing significant physical, psychological, and social harm. Examples of these are bladder and bowel issues, such as incontinence, malabsorption, pain and lymphoedema.[9]

> "I was feeling really frustrated, even though I was in remission from cancer I was having quite extreme side effects which were not settling despite being told that after eight or nine months it would…but it did not. It has been really difficult to deal with."
>
> *Late effects service patient 2024- completion of Radiotherapy 2022.*

Recent evidence shows that between 5 to10% of men treated for prostate cancer experienced at least one gastrointestinal complication requiring a procedural or surgical intervention within two years after radical radiotherapy[10]. Living With and Beyond Cancer (LWBC) guidance[11] has provided an important framework to address the needs of patients following cancer treatment. However, significant gaps persist at the national level in the availability of services specifically dedicated to managing the late effects of radiotherapy. Patients referred to existing national specialist centres face significant issues accessing these centres. These include long travel times, which are not only expensive but also distressing and debilitating, as many patients are experiencing symptoms such as bladder and bowel incontinence. Challenges in supporting patients with post-treatment symptoms are multifaceted. Key barriers include insufficient service funding, limited education and training for healthcare staff, and inadequate national recognition of the importance of this patient cohort. These issues collectively hinder the delivery of comprehensive, effective care for individuals experiencing the long-term consequences of cancer treatment.

[9] Towards Safer Radiotherapy 2019 IPEM
[10] National Prostate Cancer Audit 2023
[11] Living with and beyond cancer 2013

3. National Context

The 2019 Modernising Radiotherapy service specification[12] states it is the responsibility of all the radiotherapy providers to prevent and minimise late effects through better targeted treatments, provision of information and the management of side effects.

Local: Most patients that develop late effects following radiotherapy treatment should be managed locally as an integral part of rehabilitation or as part of locally stratified follow-up care pathways. This should include options for referral to local specialties / services that have expertise to manage more common late effects.

Specialist: Specialist late effects centres will manage and co-ordinate the provision of specialist services for complex late effects of cancer treatments and align to specialist cancer surgery and other treatment pathways as they arise.[13]

Services providing both adult and paediatric radiotherapy are commissioned via Specialised Commissioning. Currently, there are very few dedicated services specifically for adult radiotherapy late effects, although commissioned services and long-term follow-up exist for children,[14] [15] which indicates there is an unmet need for the adult population. It is significant to note that most radiotherapy centres do not offer dedicated services for late effects, highlighting the unique nature of this programme.[16] This recent survey abstract highlighted seventeen late effects services with no consistent service model and **not one is a commissioned service**.

Figure 3 Summary of Late effects service provision across England

Category	Details
Total responses	34 out of 52 radiotherapy providers
Sites with Late Effects Services	17
Sites with services in development	2
Focus of existing services	Primarily pelvic late effects
Radiotherapy-specific services	19
Therapeutic Radiographer-led services	19
Multidisciplinary team-led services	6

[12] 2019 Service Specification; Adult External Beam Radiotherapy Services
[13] 2019 Service Specification; Adult External Beam Radiotherapy Services
[14] NHS commissioning » Children and young people's cancer service portfolio (england.nhs.uk)
[15] Quality statement 6: Follow-up and monitoring of late effects | Cancer services for children and young people | Quality standards | NICE
[16] A Survey of Late Effects Service Provision Across England

The survey collected 34 out of 52 possible responses, identifying adult Late Effects Services across the UK. The responses are from England, with **fourteen initially funded by Macmillan**. Most services targeted pelvic late effects, with 56% being radiotherapy-specific and 59% led by radiographers. Some were run by multidisciplinary Allied Health Professional teams (18%).

Existing services, led by a range of health professionals, primarily focus on retrospectively managing patients who have already developed late effects or signposting to other specialties. However, Therapeutic Radiographers possess a unique set of skills and knowledge that spans the entire radiotherapy pathway, including dosimetry, treatment delivery, and acute side effect management. Their specialised training provides a unique opportunity to improve patient outcomes by predicting or preventing late effects, rather than waiting for life-changing symptoms to appear. They can therefore offer more proactive and prospective management for patients, potentially mitigating the severity or occurrence of late effects and ultimately delivering an optimal model of care for patients suffering from radiotherapy late effects.[17] Despite their crucial role, Therapeutic Radiographers with an interest in late effects often work in isolation, with limited opportunities for discussion or access to formal guidance. This lack of support can hinder their ability to share knowledge and best practices effectively.

4. Local context

The SWRLES aim is to support people living with long term effects caused by radiotherapy treatment to have prompt access to local and regional services. Improving access to dedicated Radiotherapy Late Effects Services (RLES) has been a longstanding priority for radiotherapy providers in the Southwest (SW) region to address issues of inconsistent access.

Prior to the development of the SWRLES the following services were available across the SW geography for patients experiencing late effect symptoms.

- **Taunton, Somerset:** has had a Therapeutic Radiographer(1.0WTE) led service since October 2014. This was introduced following a Patient Advice and Liaison Service (PALS)

[17] Improved models of care for cancer survivors

complaint from a prostate cancer patient who had late effects that were not being effectively managed.

- **Cheltenham**: Patients have had access to a constrained Therapeutic Radiographer led service (0.2 WTE) for two years, funded non-recurrently by a local cancer charity.
- **Bath**: Patients could access the Pain Related Complex Cancer Late Effects Rehabilitation Service (CCLERS) for highly complex side effects management. However, this service is not specific to radiotherapy late effects and requires patients to have been seen by local pain, rehabilitation, and/or late effects services first without improvement in symptoms. It is a national tertiary service funded by NHSE[18] run by a multidisciplinary team and patients need to be experiencing serious complex late effects to be eligible to access.
- **Other Centre's**: No other radiotherapy centres in the SW region provided access to a RLES.

The Somerset service provides clinical expertise from a Consultant Therapeutic Radiographer and a single point of access for patients who experience challenges navigating the healthcare system. Somerset is part of the Somerset, Wiltshire, Avon, and Gloucestershire (SWAG) Cancer Alliance region. To provide greater equity of access across the SWAG region, Macmillan has funded the establishment of similar RLES in Bristol, Bath, and Cheltenham as part of a two-year pilot program. Additionally, to extend the reach across the wider SW, providers within the Peninsula Cancer Alliance region joined the pilot, offering services in Exeter, Torbay, and Truro. This development and expansion of late effects services across the SW, represent a significant advancement in patient care for those experiencing long-term effects of radiotherapy.

The dataset collected from these services was used was a critical resource for the evaluation. Combined with the legacy dataset from the longstanding Somerset RLES, it offered a uniquely valuable tool for assessing service effectiveness and shaping future healthcare strategies. With investment from Macmillan Cancer Support and SWAG Cancer Alliance, the SWRLES two-year pilot project, formally launched in 2022 with the initial aim to enhance and expand access to RLES across the region. Details about the expansion in services is shown below:

[18] The National CRPS and Complex Cancer Late Effects Rehabilitation Service, Bath

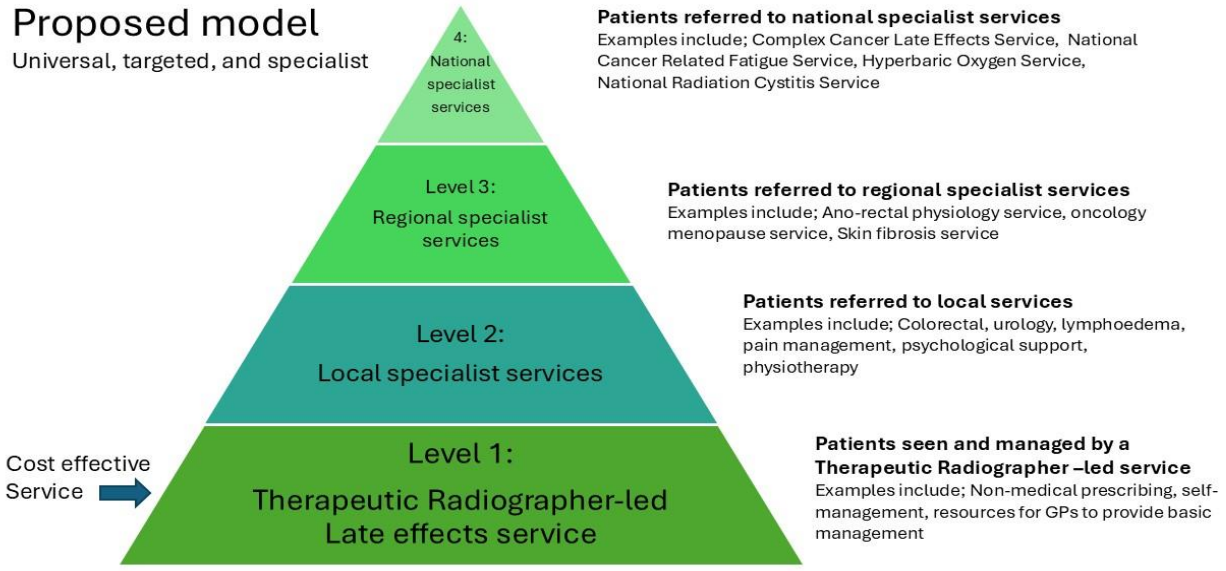
- **Taunton, Somerset**: The existing service was strengthened from an administrative perspective to support its well-established programme and the expansion across the SW with the addition of a SWRLES Band 4 Navigator(1.0WTE).
- **Cheltenham, Gloucestershire**: Access to the existing RLES was increased from 0.2 WTE to 0.8 WTE, significantly enhancing service availability provided by the current Therapeutic Radiographer.
- **Bath & Bristol**: Both radiotherapy centres provided access to a 1.0 WTE Therapeutic Radiographer led RLES.
- **Peninsula (Truro, Torbay & Exeter)**: These three radiotherapy departments secured their own short term internal funding to introduce a Therapeutic Radiographer led RLES, highlighting the Trusts' financial contributions towards expanding access.

This nationally recognised, Macmillan award-winning, project introduced a groundbreaking regional model for comprehensive late effects services for radiotherapy patients across the SW. As a first of its kind, it aimed to address previous disparities in access to care, ensuring improved patient outcomes and providing a personalised cancer care pathway. Additionally, the project created opportunities to share best practices and support ongoing research in late effects management.

Summary of the Regional Service Model

The ambition of the regional service is to implement a model that aligns with the NHS Comprehensive Model for Personalised Care. This aims to empower people to manage their care and the impact of their cancer. The desire is every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing. All patients, including those with secondary cancers, will have access to the most appropriate expertise and support as shown in Figure 4.[19]

Figure 4: Proposed regional service model.



Level 1: The goal is to deliver autonomous care, minimising the need to refer patients to secondary services, as they often already attend multiple appointments. By training Therapeutic Radiographers in non-medical prescribing and diagnostic referrals, a holistic and consistent care model can be achieved. This Therapeutic Radiographer led approach not only enhances patient care but also alleviates pressure on secondary services, such as gastroenterology.

[19] NHS England » Comprehensive model of personalised care

Evidence from the ALERT-B audit[20], supported by professional feedback, confirms that this model does not impose an additional burden on secondary care resources.

Level 2: Therapeutic Radiographers develop pathways and coordinate referrals into local services like colonoscopies and bladder instillations, making it easier for patients to receive routine care closer to home. Unlike radiotherapy, which is available at limited sites, these services are more widely accessible.

Level 3: To ensure patients can access specialised regional services, like menopause specialists and skin fibrosis treatments. Patients are willing to travel for these services, supported by their Therapeutic Radiographer at the referring site.

Level 4: Highly specialised services, such as those for functional pain and radiation cystitis, are reserved for patients who have exhausted all other options. Therapeutic Radiographers ensure appropriate triage and referrals are in place and patients can return to local services for follow-up care after specialist interventions.

[20] Alert B Audit 2016

5. Evaluation Aims and Methodology

The SW Radiotherapy Late Effects pilot launched on 1st of August 2022. During 2022/23 NHS South Central and West Commissioning Support Unit (SCW) was commissioned by SWAG to design and deliver the late effects services evaluation. This included establishing information governance arrangements to enable consistent data collection across all sites delivering a RLES within the region.

5.1 Key Performance Indicators

The services collected a pre-defined set of key performance indicators (KPIs) to facilitate a comprehensive evaluation. These KPIs provide a structured framework for developing and assessing the service's impact on patient care and resource allocation. Additionally, these KPIs were agreed with Specialised Commissioning prior to data collection.

Figure 5: Key Performance Indicators.

KPI Description	Tool/Data Source	Rationale	Data items
Theme 1: **A Radiotherapy Late Effects Service is required**	**Referrals dashboard** Basic services numbers	To understand burden of radiotherapy late effects and how, and when, patients access a late effects service.	Descriptive statistics • Cancer diagnosis • Age • Time since radiotherapy completed • Site treated • Treatment centre (local patients / legacy patients) • Who referred the patient
		Current follow up pathways assess patients for cancer recurrence not late effects. Are these patients on existing follow up pathways or beyond? What symptoms do patients have?	• Follow-up pathways and delivery model: face-to-face, phone, remote monitoring, GP led or none • Tick box of main symptoms: pain, bowel function, fatigue etc.

	Macmillan Concerns Checklist (HNA - Holistic Needs Assessment)	What are the patient concerns, and how do these compare to other parts of the cancer pathway such as diagnosis, end of treatment etc.	• Main concerns symptoms: physical, emotional, family, financial, spiritual • Distress thermometer (NHS benchmark)
	Cancer Registry and MDT	SWAG Cancer Alliance identified the need to improve the accuracy of cancer registers, hugely beneficial as we currently rely on historical data from charity partners to define the scale of the problem. All patients seen in a regional late effects clinic are registered and have the potential for MDT discussion	• MDT spreadsheet and meeting minutes
THEME 2: **A Regional Radiotherapy Late Effects Service Model is effective both in improving patient outcomes and financially**	**Outcomes dashboard:** Quality of Life: EQ 5D-5L and EORTC QLQ C30 questionnaires	Evidence the burden of radiotherapy late effects on quality of life. How does this compare to national cancer quality of life data?	• Functional and symptom scores – overall quality of life on referral and discharge from the late effects services
	Symptom management: Site specific EORTC questionnaires	Demonstrate the symptom profiles of late effects. Investigate if late effects interventions and pathways improve symptoms and patient outcomes	• Symptoms scores on referral and discharge from the late effects services
	Patient understanding / activation of self-management	Understand if patients have the skills and knowledge to self-manage late effects	• Validated questionnaire on referral and discharge from the late effects services
	Referral dashboard:	Audit practice against a radiotherapy service specification standard	• Specific bowel symptoms for pelvic radiotherapy patients

	ALERT-B questionnaire Referral pathways and levels of care Late Effects services use mapping **Somerset data:** Secondary care usage Primary care usage, medication use	Define routes of referral and evidence costs of services Evidence equity of services across the region Patterns of secondary care usage and costing. Does a late effects service reduce costs? Are patients with late effects high service users of primary care? Without correct reporting data for this cohort will always be hidden.	• Providers / services referred on to and managed by levels of referrals (1-4) • Postcode mapping • Analysis of service use of outpatient appointments, unplanned admissions, emergency care • SNOMED coding and case studies
THEME 3: **A Radiotherapy Late effects service is valued by patients and service providers**	**Qualitative data** What matters to you? NHS Friends and family questionnaire Service provider feedback Focus group feedback	Thematic analysis and content analysis, natural language modelling To understand what's important following cancer treatment Understand if patients find the service useful and how we can improve Are we increasing or burdening other services with referrals? What should late effects services look like?	**On referral:** • What matters to you? • Were you aware radiotherapy could cause late effects? • Where / how long have you been seeking help for your late effects? **On discharge:** • Service rating and open questions • Referrers questionnaire, were you aware of late effects services, has it increased / decreased referrals to your service, does a late effects service benefit your patients? • Thematic analysis

5.2 Methodology for healthcare utilisation

Prior to the establishment of the SWRLES, it was reported that patients demonstrating symptoms that could indicate radiotherapy late effects saw their GP multiple times before secondary care referral, presented more often in an emergency setting, and were referred onto multiple elective pathways with resulting inefficiencies in healthcare provision. The evaluation

sought to evidence these anecdotal findings. The challenge to understand and quantify the impact of LES on efficiency, cost-effectiveness, and patient experience is the limited availability of long-term data, variability in service provision, and the complexity of tracking patient outcomes across different healthcare pathways.

The decision was made to use the legacy **Somerset data** for evaluating healthcare utilisation. Given the longevity of the service, this dataset provides a substantial foundation for evaluation. The extensive data, encompassing both pre- and post-implementation of the late effects service, offers mature and robust insights into the secondary healthcare utilisation of radiotherapy patients. This unique dataset supports a comprehensive analysis of the service's impact on patient care and resource allocation.

The analysis was conducted using the following criteria:

- **Pseudonymisation**: NHS numbers of Somerset radiotherapy patients were pseudonymised to link with Secondary Uses Service (SUS) datasets for emergency department (ED) attendances, outpatient appointments (OP), and non-elective (NE) admitted patient care.
- **Quantifying Acute Activity**: This linkage allowed the quantification of acute activity for radiotherapy/LES patients before and after their RLES referral.
- **Activity Rates Calculation**: To compare levels of acute activity before and after RLES referral, activity rates were calculated based on 'Days at Risk'
- **Days at Risk (Pre-RLES):** This was defined as the number of days between cancer diagnosis and RLES referral, excluding the first-year post-diagnosis, to rule out post treatment acute toxicity.
- **Days at Risk (Post-RLES):** This was defined as the number of days between RLES referral and today, or RLES referral and the date of death (due to inconsistent data recording the 30th of June as a synthetic death date).
- **Calculating Activity Rates**: Counts of ED attendances, OP appointments, and NE admissions (excluding the first-year post-diagnosis) before and after RLES referral were divided by the relevant 'Days at Risk' and multiplied by 1,000 to get activity rates per 1,000 Days at Risk. See the example for prostate cancer radiotherapy patients in section 6.2.

Dataset Cohort Profile

Between 2009 and 2022, a total of 14,831 patients underwent radiotherapy at the Beacon Centre, Somerset. Of these, 561 patients were referred to the original local late effects service. Finally, a cohort of 349 patients who had received radical or adjuvant treatment (with a minimum of 12-months between diagnosis and late effects referral were identified. (Figure 6). The cohort encompassed a diverse range of tumour sites, allowing for a comprehensive comparison of patient service utilisation and a more detailed analysis of how different tumour type influence healthcare usage and overall patient outcomes The cohort consisted of 163 males and 189 females. Figures 7 and 8 illustrate the distribution of age at diagnosis and age at referral into the RLES.

Figure 6: Diagram to demonstrate Somerset patient referral cohort.

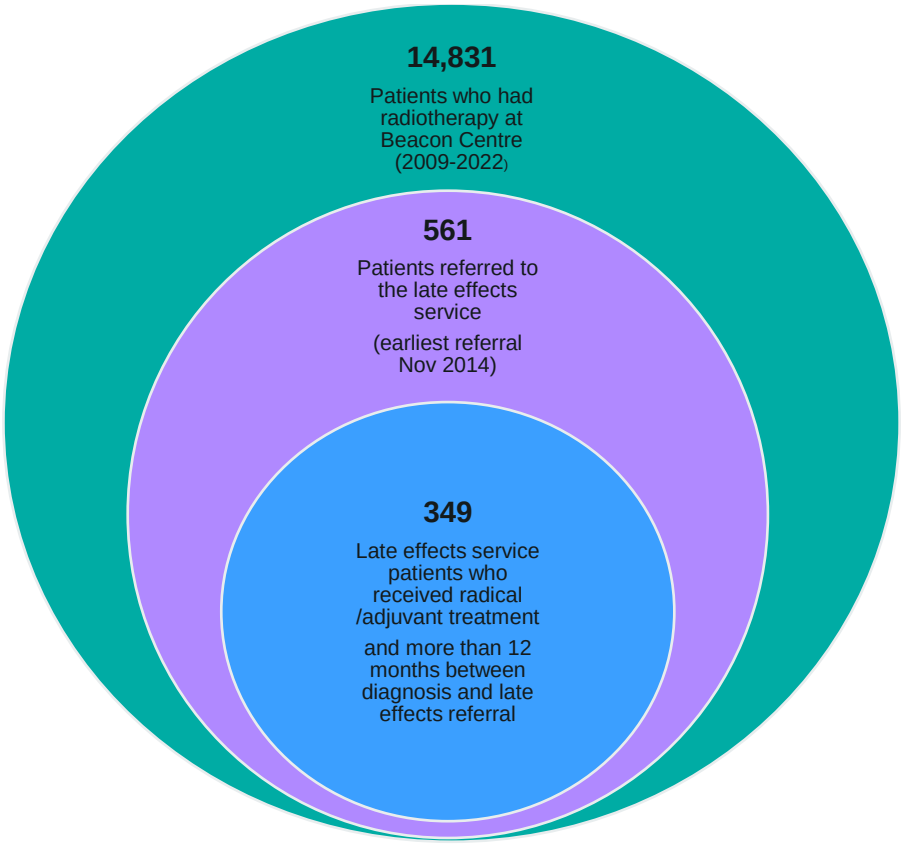


Figure 7: Age of Somerset patients at diagnosis

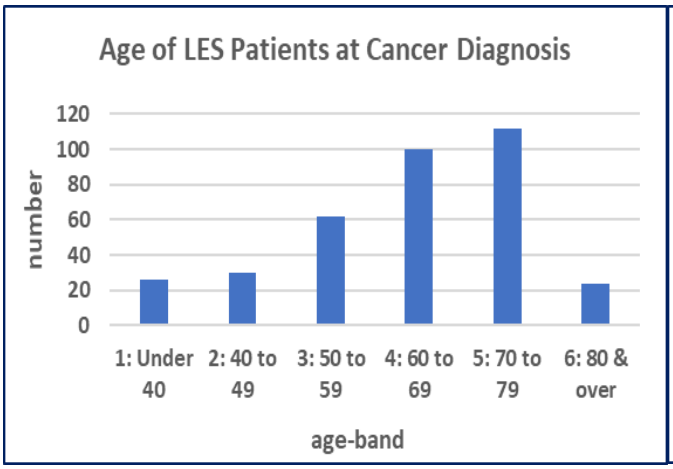


Figure 8: Age of Somerset patients at referral to RLES

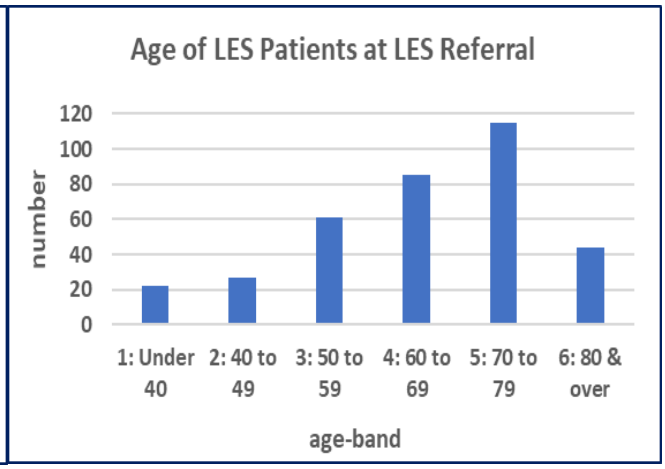


Figure 9: Interval between diagnosis and refer to RLES

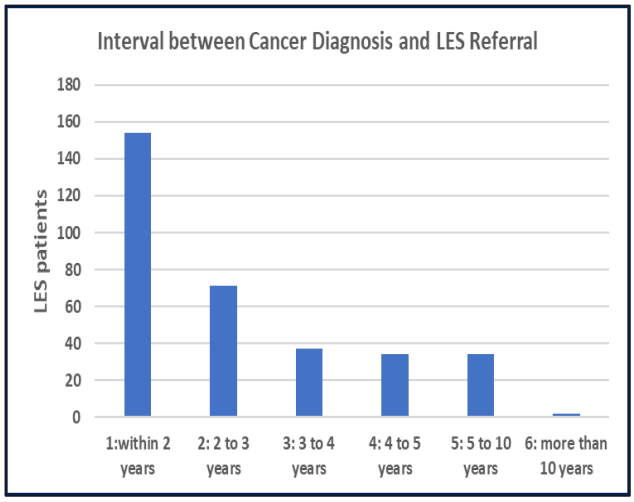


Figure 10: Tumour sites referrals in RLES data

	RLES Patients in Cohort
Prostate	153
Breast	116
Gynaecological	59
Colorectal	7
Other	6
Head & Neck	5
Bladder	1
Skin	1
Upper GI	1
ALL Cancers	**349**

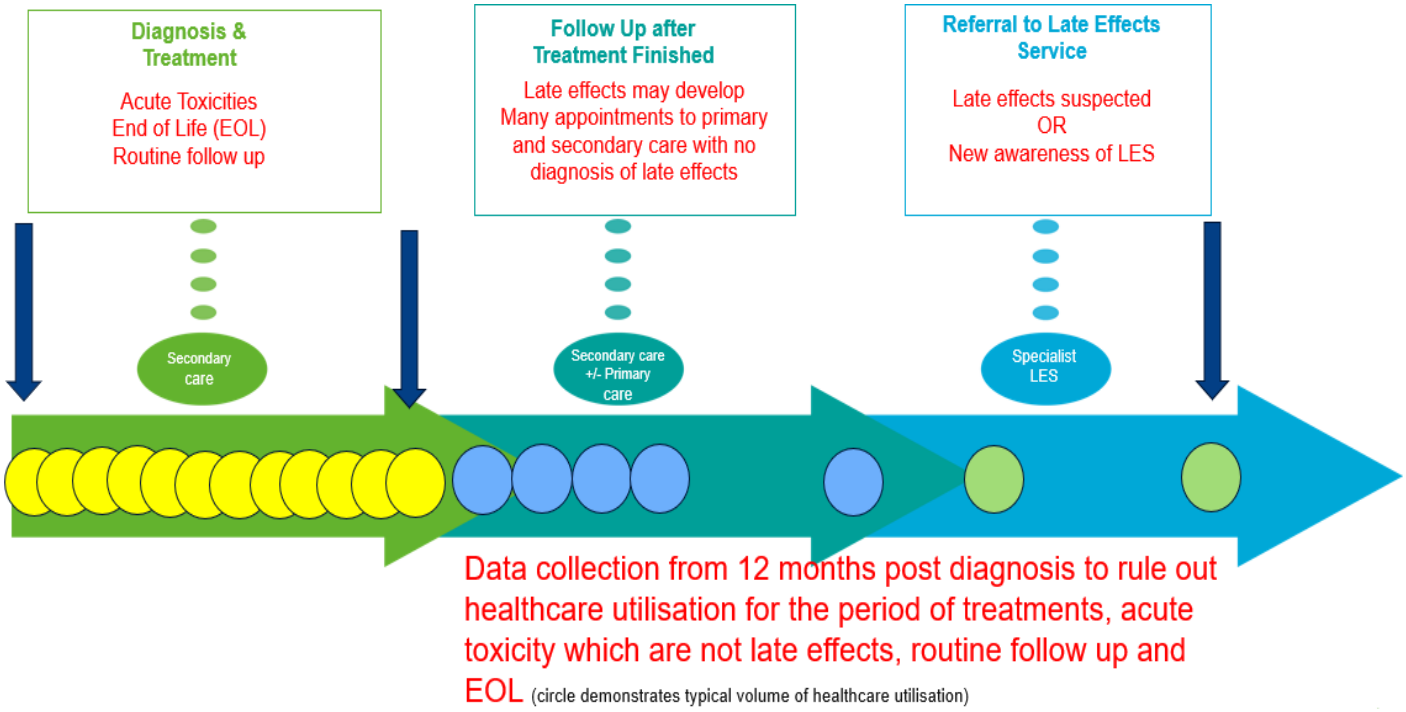
5.3 Somerset legacy patient cohort

Patient Referrals and Timeline

A sample of 349 radiotherapy patients were identified, including those receiving radical and adjuvant treatment, referred to the Somerset RLES. These referrals occurred at least one year following their initial cancer diagnosis and were screened to ensure symptoms were consistent with late effects following radiotherapy. Palliative patients were excluded due to the probability of being high secondary care service users due to the stage of disease. The earliest referral

date to RLES is November 2014, with the earliest cancer diagnosis date being October 2009. This timeline allowed for a significant period of data collection and analysis.

Figure 11: Somerset data collection timeline



5.4 Analysing Healthcare Utilisation methodology

The Secondary Uses Service (SUS) data analysis has been refined by incorporating specialties and specialty Healthcare Resource Group (HRG) codes into the OP and NE data, as well as Emergency Medicine Investigation data into the ED data. This refinement allows for the attachment of costs, based on the National Tariffs for 2022/23, to the activity.

5.41 A comprehensive application to healthcare data involves systematically using data to improve patient care, enhance operational efficiency, support clinical decision-making, and optimise resource allocation. This approach integrates various healthcare data sources, applies advanced analytics, and ensures compliance with regulations to inform. This method has been applied to:

- Each specialty for OP
- Each HRG chapter for NE admissions
- Each investigation category for ED attendances

This approach accounts for the differing tariff costs across outpatient specialties, HRG chapters in admitted care, and investigation categories in ED. This detailed costing approach provides a more accurate and comprehensive understanding of the financial implications of the RLES on healthcare utilisation.

5.42 Further, changes in appointment episodes per 1,000 Days at Risk for each specialty/HRG chapter/investigation category are assessed for significance. Results highlight those areas where the change before and after RLES is significant at a 95% confidence level, based on a T-test of the corresponding rate values. (see figure 12)

6. Healthcare Utilisation Outcomes

Outpatient Attendances:

The patterns of outpatient attendance observed for radiotherapy patients before and after their referral to a RLES imply strongly that engagement with a RLES reduces the level of outpatient attendance for these patients. When these patterns take account of the various specialties of these attendances it appears clear that there is significant cost-avoidance associated with referral to a RLES.

Figure 12: OP utilisation and associated cost avoidance

Cancer site: ALL; Age at Diagnosis: ALL: Age at LES Referral: ALL: ICB: ALL	OP Appointments Before LES	OP Appointments After LES
Total OP Appointments (from 1 year after diagnosis)	**5869**	**10160**
Total 'Days at Risk (from 1 year after diagnosis)	**264818**	**464736**
OP Appointments per 1000'Days at Risk'	**22.16**	**21.86**

Estimated 'savings': ALL cancer(s)	Since service began	During 2023
Estimated OP Appointments 'saved'	**273**	**67**
Estimated OP cost 'avoidance'	**£50,456**	**£12,353**
Estimated OP Appointments 'saved' *	**751**	**184**
Estimated OP cost 'avoidance' *	**£96,914**	**£23,728**

***These findings were significant at a 95% confidence level**

Non-Elective Admissions:

Radiotherapy patients engaged with a RLES are less likely to have unplanned hospital admissions post-referral. Among the 15 most common admitting specialties, 11 show reduced admissions after RLES referral. Beyond the financial benefits, reduced non-elective admissions improve patient flow and waiting-list management.

Figure 13: Non elective admission utilisation and associated cost avoidance

Estimated 'savings': ALL cancer(s)	Since service began	During 2023
Estimated Non-Elective admits 'saved'	**337**	**82**
Estimated Non-Elective cost 'avoidance'	**£764,985**	**£187,296**
Estimated NE admits 'saved' *	**340**	**83**
Estimated NE cost 'avoidance' *	**£774,602**	**£189,650**

***These findings were significant at a 95% confidence level**

ED Attendance:

Significant reductions are seen in ED attendances once a patient has been referred to the late effects service. Fewer ED visits contribute to easing pressure on emergency departments, allowing resources to be allocated more efficiently while also reducing waiting times for other patients.

Figure 14: ED utilisation and associated cost avoidance

Estimated 'savings': ALL cancer(s)	Since service began	During 2023
Estimated ED attends 'saved'	**99**	**24**
Estimated ED cost 'avoidance'	**£6,957**	**£1,703**
Estimated ED attends 'saved' *	**121**	**30**
Estimated ED cost 'avoidance' *	**£13,034**	**£3,191**

***These findings were significant at a 95% confidence level**

See Appendix 1 for an example of the dashboard created to display data used for healthcare utilisation.

6.1 Comparative Analysis: Patients Without Late Effects

To create a comparison group of patients not experiencing late effects, a sample of 401 radiotherapy patients was selected based on the following criteria:

- The patient's pseudo-NHS number is listed among radiotherapy patients.
- The patient has no referrals to any RLES.

Figure 15: Comparison group utilisation data

	Radiotherapy patients WITH a late effects referral			Radiotherapy patients with NO Late Effects Referral
	Prior to LES Referral	After LES Referral	Total	
Outpatients Appointments per 1000 days	**22.2**	**21.9**	**22.0**	**13.1**
Non- Elective Hospital Admissions per 1000 days	**1.56**	**0.83**	**1.10**	**0.72**

This comparison of Radiotherapy patients who present with late effects demonstrates a significantly higher likelihood of requiring both outpatient, non-elective inpatient and emergency care compared to those who do not experience late effects. Notably, before their referral to the RLES, these patients are more than twice as likely to undergo an unplanned hospital admission. This increased healthcare utilisation underscores the critical role of RLES in managing late effects, potentially mitigating the need for acute care interventions and improving long-term patient outcomes.

6.2 Worked example of the healthcare burden and financial impact by tumour site: Prostate Secondary care utilisation

As an illustrative example, consider the OP activity for prostate cancer patients:

- Before LES Referral: There were 2,242 outpatient (OP) appointments over a period of 112,681 days at risk, which translates to an activity rate of 19.87 appointments per 1,000 days at risk.
- After LES Referral: The number of OP appointments increased to 4,069, with the days at risk extending to 219,807. However, the activity rate slightly decreased to 18.51 appointments per 1,000 days at risk, indicating that OP referral rates decrease post-LES referral.

- By applying the pre-LES activity rate to the post-LES days at risk, it is estimated that there would have been 4,366 OP appointments, which is 297 more than actually occurred.
- Given the specialty cost of £226 per appointment, these 297 fewer appointments result in a total saving of £67,234, or £24,540 annually.

The data indicates that RLES referrals might result in fewer OP appointments, which could imply changes in patient management and procedural efficiency. This reduction not only saves costs but also potentially lessens the burden on healthcare services, allowing resources to be allocated more efficiently. Furthermore, the annual savings of £24,540 can be significant for budget planning and resource allocation in healthcare facilities catering to prostate cancer patients.

Figure 16: Healthcare utilisation for patients with prostate cancer

Cancer Site: PROSTATE; Age at Diagnosis: ALL; Age at LES Referral: ALL; ICB: ALL	Non-Elective Admissions before LES	Non-Elective Admissions After LES
Total Non-Elective Admissions (from 1 year after diagnosis)	**93**	**82**
Total 'Days at Risk' (from 1 year after diagnosis)	**112861**	**219807**
Non-Elective Admissions per 1000 'Days at Risk'	**0.82**	**0.83**

Cancer site: PROSTATE; Age at Diagnosis: ALL: Age at LES Referral: ALL: ICB: ALL	OP Appointments Before LES	OP Appointments After LES
Total OP Appointments (from 1 year after diagnosis)	**2242**	**4069**
Total 'Days at Risk (from 1 year after diagnosis)	**112861**	**221613**
OP Appointments per 1000 'Days at Risk'	**19.87**	**18.36**

The analysis indicates a decrease in OP appointment episodes following referral to the RLES. If the pre-RLES activity rate were applied to the post-RLES "Days at Risk," an estimated 4,402 OP appointments would be expected, 333 more than were recorded. By applying the mean cost of £183 per appointment, these 333 avoided appointments represent a total cost-avoidance of £61,007 over the lifetime of the RLES. This equates to an estimated annual cost avoidance of £14,705, highlighting the financial and OP resource and capacity efficiencies associated with the service for just one diagnosis type.

6.3 Healthcare Utilisation Summary

The significant financial cost avoidance observed in outpatient attendances, non-elective admissions, and ED attendances underscore the value of continued investment in RLES services. Additionally, the reduction in non-elective admissions highlights substantial operational benefits, including enhanced patient flow and improved waiting-list management.

This analysis has been refined by including Specialties and Specialty/HRG Codes in the OP and NE data, and Emergency Medicine Investigation data in the ED data, which enables costs (based on National Tariffs for 2022/23) to be attached to the activity.

- For OP activity the costs of a Single Professional First Appointment by Specialty are used
- For NE activity the mean spell costs of HRG codes by Specialty are used
- For ED activity the Investigation Category costs are used.

Figure 17: OP speciality service utilisation

	All Cancers (354) **Significantly lower** • Clinical Oncology • Medical Oncology • Gynae Oncology **Significantly higher** Physiotherapy - expected		**Prostate (155)** **Significantly lower** • Clinical Oncology • Medical Oncology **Significantly higher** Physiotherapy - expected		**Breast (118)** **Significantly lower** • Breast Surgery **Significantly higher** Physiotherapy - expected		**Gynae (60)** **Significantly lower** • Clinical Oncology • Gynae Oncology **Significantly higher** Physiotherapy	
Estimated Savings	Since Service Began	During 2023	Since Service Began	During 2023	Since Service Began	During 2023	Since Service Began	During 2023
Estimated OP appointments 'saved' or 'avoided'	273	67	639	147	-136	-39	420	89
Estimated OP costs 'avoidance'	**£50,456**	**£12,353**	**£93,013**	**£21,459**	**-£26,553**	**-£7,679**	**£55,029**	**£11,687**
Estimated OP appointments 'saved' SIGNIFICANT	751	184	549	127	28	8	413	88
Estimated OP costs 'avoided' SIGNIFICANT	**£396,914**	**£23,728**	**£86,962**	**£20,063**	**-£3,059**	**-£888**	**£54,746**	**£11,627**

Figure 18: HRG chapters utilisation

	All Cancers (354) **Significantly lower** Digestive, infection /immunity, cardiac, respiratory, musculoskeletal, urinary tract, skin, oncology, ENT, hepatobiliary, vascular, female reproductive system, trauma **Significantly higher** Nervous system, endocrine undefined		Prostate (155) **Significantly lower** Cardiac, digestive, infection/immunity disorders, urinary tract & male reproductive system, respiratory, trauma, ENT, skin **Significantly higher** Musculoskeletal, nervous system, endocrine		Breast (118) **Significantly lower** Infection/immunity, digestive, respiratory, musculoskeletal, cardiac, oncology, skin, vascular, hepatobiliary, ENT **Significantly higher** Nervous system, urinary tract, undefined, endocrine		Gynae (60) **Significantly lower** Urinary tract, infection/immunity, cardiac, female reproductive, skin, vascular, ENT, endocrine, obstetrics **Significantly higher** Digestive, musculoskeletal, respiratory, nervous, trauma	
Estimated Savings	Since Service Began	During 2023	Since Service Began	During 2023	Since Service Began	During 2023	Since Service Began	During 2023
Estimated NEA admissions 'saved' or 'avoided'	337	82	44	10	191	55	41	9
Estimated NEA costs 'avoided'	£764,985	£187,296	£90,282	£20,829	£445,092	£128,712	£93,910	£19,945
Estimated NEA admits 'saved' SIGNIFICANT	640	83	44	10	193	56	35	8
Estimated NEA costs 'avoided' SIGNIFICANT	**£774,602**	**£189,650**	**£85,368**	**£19,695**	**£447,489**	**£129,405**	**£78,211**	**£15,611**

The data demonstrates a significant reduction in specific types of outpatient speciality appointments and HRG chapters following RLES referral. This reduction represents the potential to efficiently allocate clinical resources and the reallocation of capacity within specialty services. Streamlining patient management of late effects results in reducing unnecessary visits, and modifying outpatient healthcare utilisation, which plays a pivotal role in enhancing both patient care and overall healthcare system efficiency.

NOTE: Due to the limited datasets from other centres involved in SWRLES, their utilisation has not been analysed in this report. It is suggested that this methodology be utilised to determine the potential total cost avoidance of all services.

6.4 Case Study Examples

The purpose of the following case studies is to illustrate the significant impact of early versus delayed referrals to the RLES. Through these real-world examples, the report aims to highlight how timely integration of RLES into patient treatment plans can lead to more efficient use of clinical resources, fewer unnecessary outpatient visits, and overall improved patient care. These case studies serve as practical evidence of the benefits of early referrals, underscoring the importance of proactive management in healthcare systems to enhance both patient outcomes and operational efficiency.

Figure 19: Early Referral to RLES

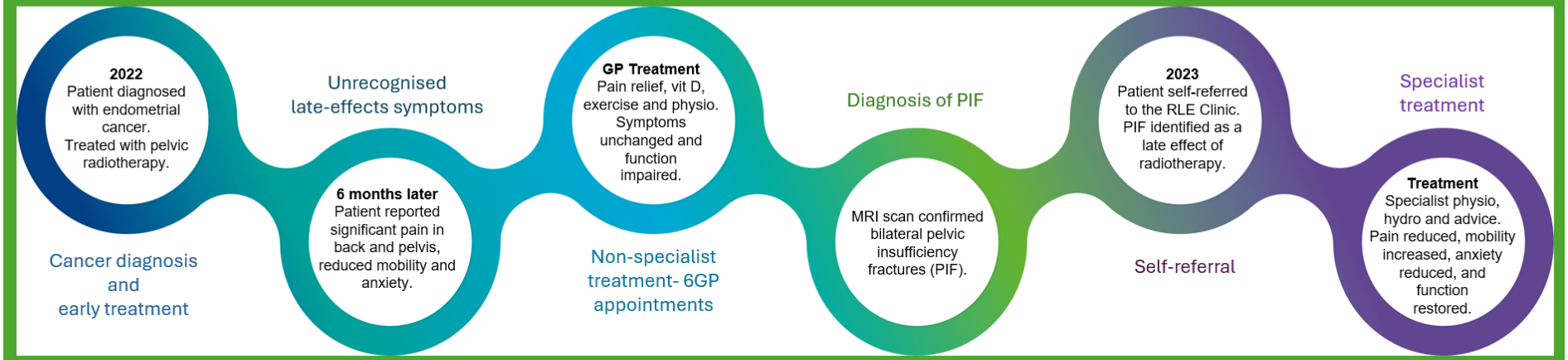
This case study illustrates a patient who was referred early to the Radiotherapy Late Effects Services (RLES). The proactive referral significantly reduced the number of outpatient specialty appointments required, the legacy patient pathway typically involved numerous visits, which could have been avoided with an early RLES referral. By integrating RLES into the patient's treatment plan at an early stage, clinical resources were effectively reallocated, and the patient's overall healthcare journey was streamlined.

Figure 20: Delayed Referral to RLES

In contrast, the second case study demonstrates the impact of not initiating an early referral to RLES. The patient's treatment plan was adversely affected due to a delayed referral. This led to a higher number of unnecessary appointments and inefficiencies in managing the patient's late effects of radiotherapy. The delayed referral resulted in a suboptimal allocation of clinical resources and highlighted the need for timely integration of specialised services to enhance patient care and reduce healthcare costs.

Figure 19: Illustration of a legacy patient pathway and how early referral to RLES resulted in timely treatment of late effects.

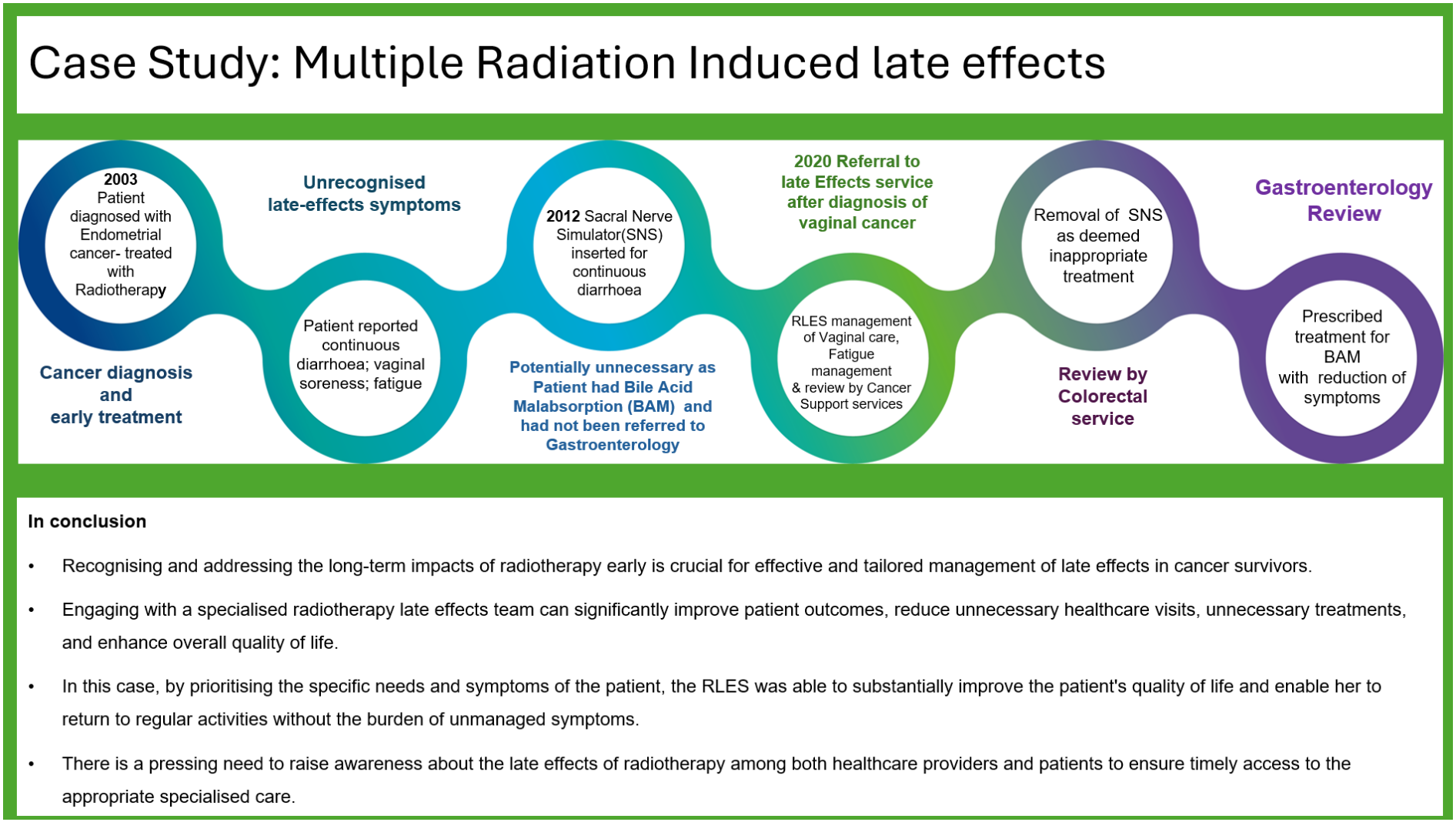
Case Study: Radiation-induced pelvic insufficiency fractures



In conclusion

- Recognising and managing the late effects of cancer treatment, such as radiation-induced pelvic insufficiency fractures, early is essential.
- Referral to - and intervention from - a specialised radiotherapy late effects team can significantly improve patient outcomes, reduce unnecessary healthcare appointments, and enhance peoples' quality of life.
- In this case, the patient was able to advocate for themselves and seek specialised care, which led to a personalised management plan that addressed their needs and a resulted in a successful outcome.
- Improved awareness of the late effects of radiotherapy amongst staff and patients is required to ensure access to the specialist treatment they need promptly.

Figure 20 Case study illustrating a patient journey where early referral to a RLES was not initiated, impacting the treatment plan



7. Patient Outcomes

It is becoming more widely acknowledged that the late effects of radiotherapy are lifelong, life-altering, and, in certain instances, life-limiting, especially as cancer survival rates continue to improve. Despite limited information on late effects, developing specialised services is essential to generate health economic data and support long-term patient care. The data used in this section is drawn from the wider **SWRLES cohort**, which established a consistent approach to collecting patient-reported outcomes (PROMs) from the inception of the pilot services. The current data collection process relies predominantly on paper format, with limited digital solutions available, resulting in a heavily administrative workload.

In September 2020, NHS England launched the national **Quality of Life Survey** (QOLS)**,** first reported in October 2021 and updated every six months. This rolling survey captures patient-reported outcomes 18 months post-cancer diagnosis, aiming to assess the impact of cancer on quality of life, identify areas of effective care or those requiring improvement, and evaluate the need for additional services. By correlating responses with diagnosis and treatment details, the survey seeks to enhance support systems, enabling individuals to live both longer and with a higher quality of life.[21] However, as the QOLS is conducted only once at 18 months post-diagnosis, it does not capture data beyond this point. Long-term monitoring of patient outcomes is crucial due to the delayed late effects of radiotherapy.

Alongside the QOL survey results the following PROMs were utilised routinely:

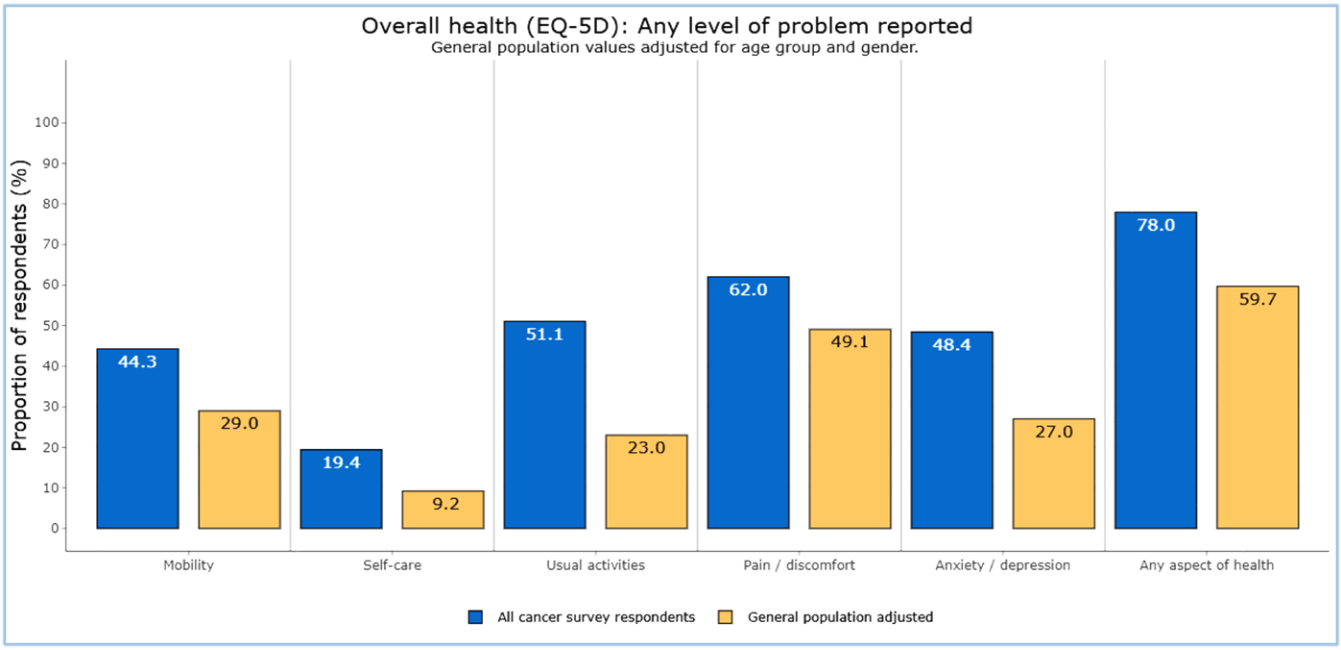
- **EuroQol (EQ) 5D-5L** a validated non-cancer standardised questionnaire-based measure of health-related quality of life (HRQoL). It is globally recognised in clinical trials, population studies, and real-world settings. It provides comparisons with other health conditions and the general population.[22]
- **European Organisation For Research And Treatment Of Cancer (EORTC) QLQ-C30** validated cancer questionnaire looks at differences in quality of life across different cancer types and different groups of patients.[23]

[21] Cancer Quality of Life Survey
[22] EuroQol
[23] EORTC

Patients enrolled in the SWRLES program complete the EQ-5D-5L and EORTC QLQ-C30 assessments at both referral and discharge. The collected data is subsequently compared with benchmarks available on the national dashboard.

The graph below compares cancer respondents to the general population, demonstrating a higher proportion of health-related issues among cancer respondents 18 months after diagnosis. This allows for a comprehensive assessment of symptom burden and overall health status in comparison to national benchmarks.

Figure 21: Percentage of people who reported any level of problem (slight/moderate or severe/unable) on each aspect of health. (December 2024)[24]



SWRLES patients also complete EORTC QLQ site-specific surveys aligned with their cancer diagnosis, providing a crucial comprehensive understanding of late effects by tumour type. These insights can inform tailored interventions, standardised pathways, and improved long-term care. To compare SWRLES outcomes with national QoL data, individual survey scores were consolidated into a single dataset for analysis by cancer site, Trust site, age, referral interval, year, and gender. The SWRLES navigator manually entered patient responses using validated scoring

[24] Cancer Quality of Life Survey

algorithms to standardise symptom and functional scores, ensuring consistency and meaningful cohort comparisons.
Each workbook supports analysis of:

- Individual patient scores at referral and discharge.
- Individual scores relative to the SWRLES patient average.
- Average scores of all SWRLES patients at both referral and discharge.

The data presented below highlights a significant disparity in quality of life (QOL) and functional well-being among patients enrolled in the SWRLES when compared to national benchmarks.

Figure 22: EORTC QLQ-C30 demonstrating people with late effects have poor quality of life

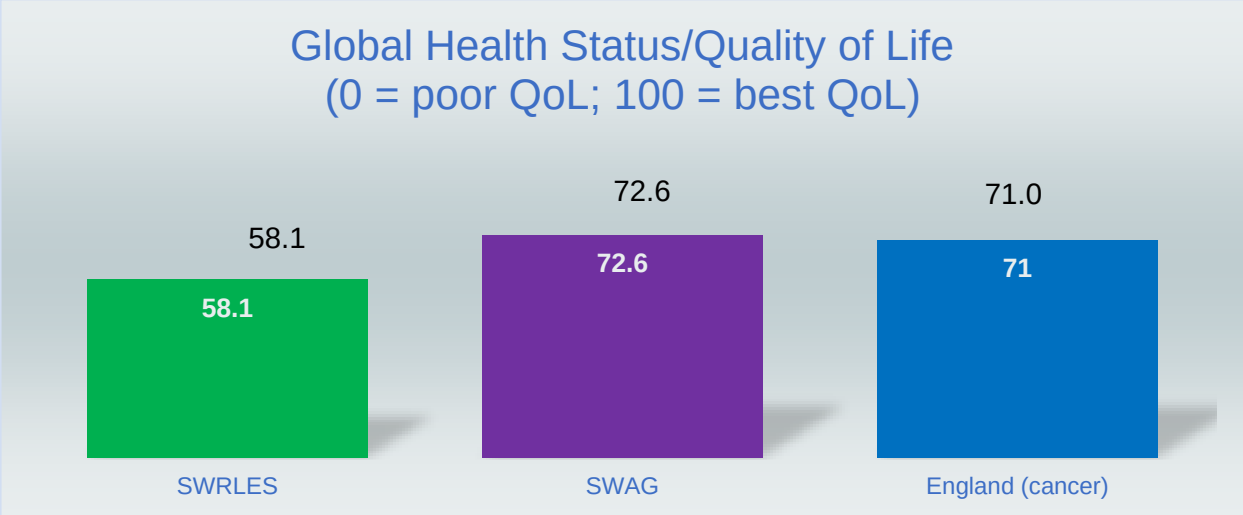
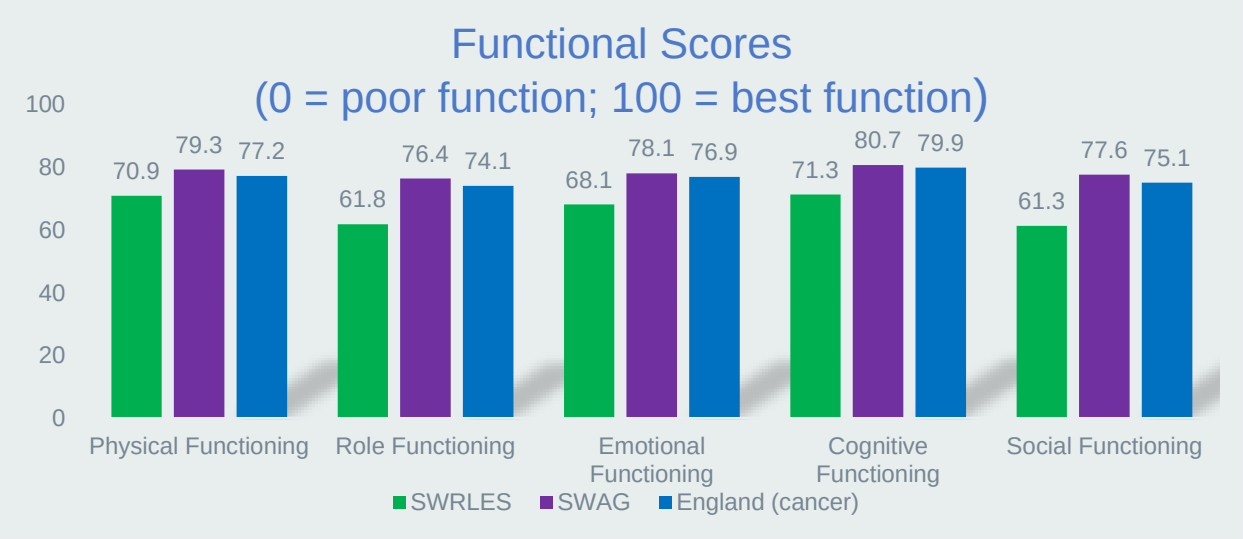


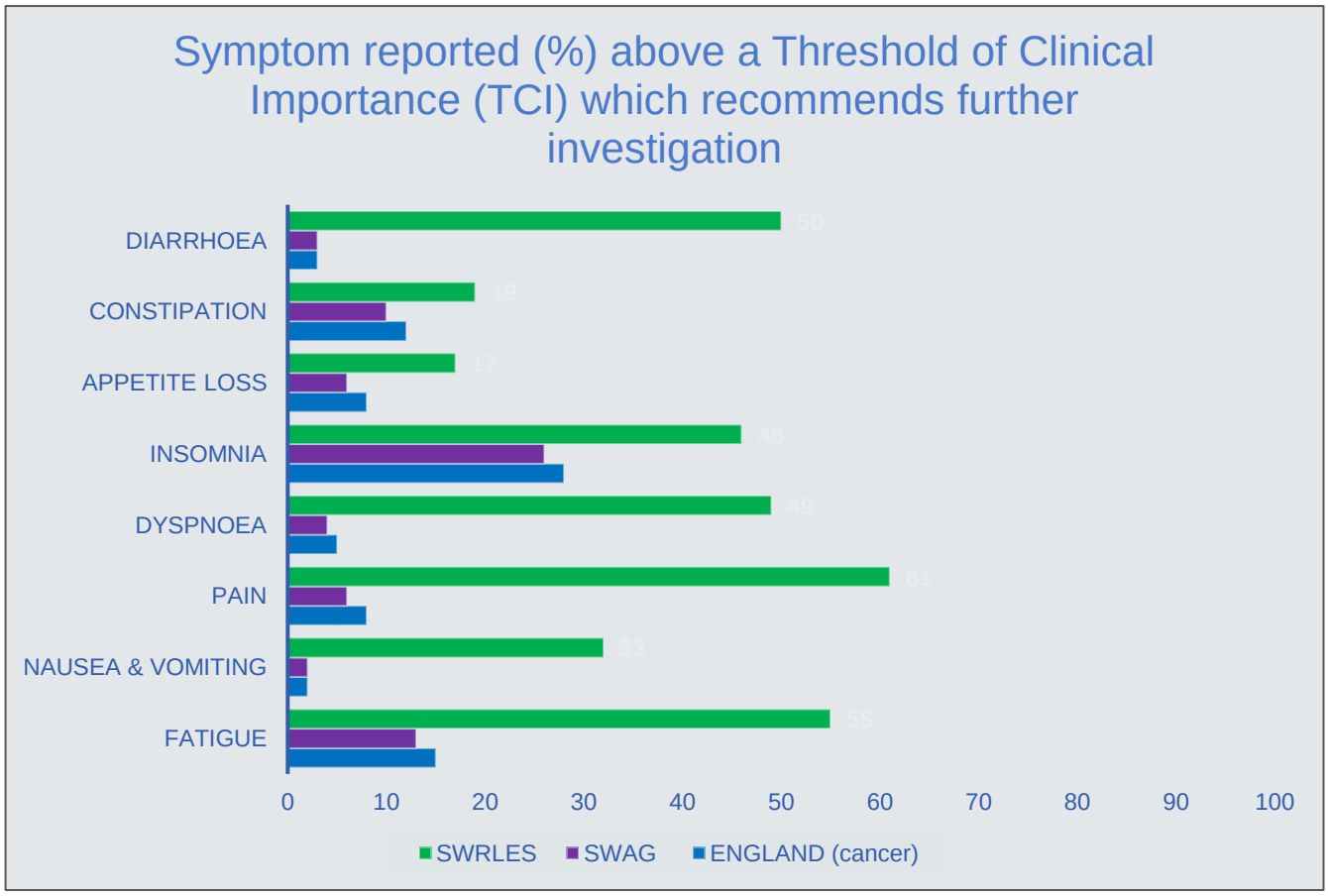
Figure 23: EORTC QLQ-C30 demonstrating people with late effects have all functional aspects of life affected



National Reference Values for Quality-of-Life.

There are published UK Reference Values for the generic EORTC-QLQ C30 QoL Survey Symptom and Functional Scores, to improve interpretation in clinical practice.[25] Scores above or below a certain threshold indicate that an individual patients' functional capacity or degree of symptoms warrants clinical Investigation. The graph below clearly demonstrates the SWRLES patients are more likely to have symptoms which warrant further investigation.

Figure 24: Graph to show patient symptoms above TCI.



This highlights the importance of a late effects services as a crucial resource for assessing and managing the symptom burden experienced by patients suffering from late effects of radiotherapy treatment. People with late effects are more likely to have symptoms which warrant further investigation.

[25] Giesinger J, *et al*. (2020). Threshold for clinical importance were established to improve interpretation of the EORTC QLQ-C30 in clinical practice and research. J Clinical Epidemiology. 118, 1-8. Doi: 10.1016/j.jclinepi.2019.10.003

Figure 25: Graph to show improvement of LE symptoms at discharge

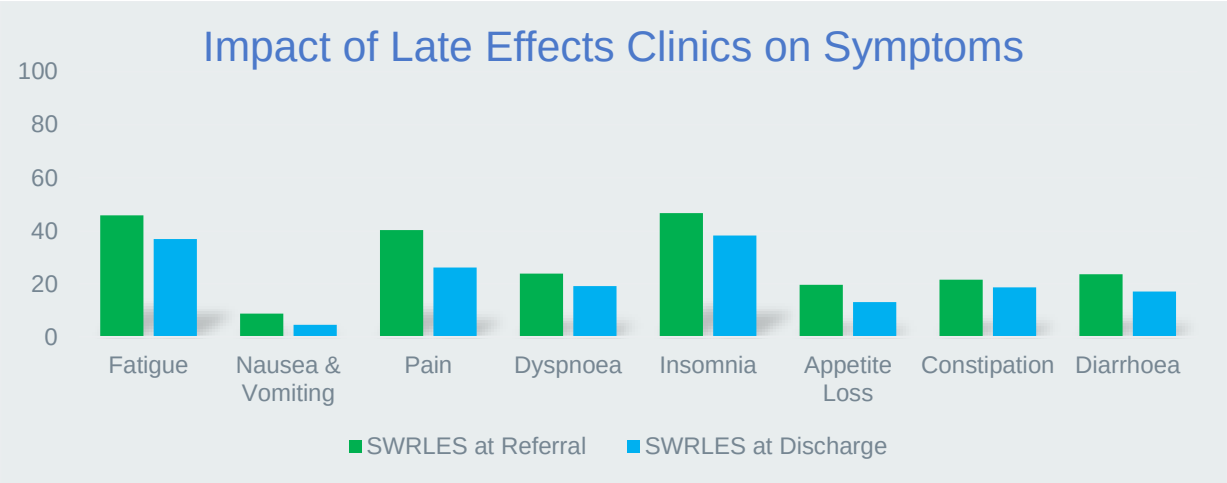
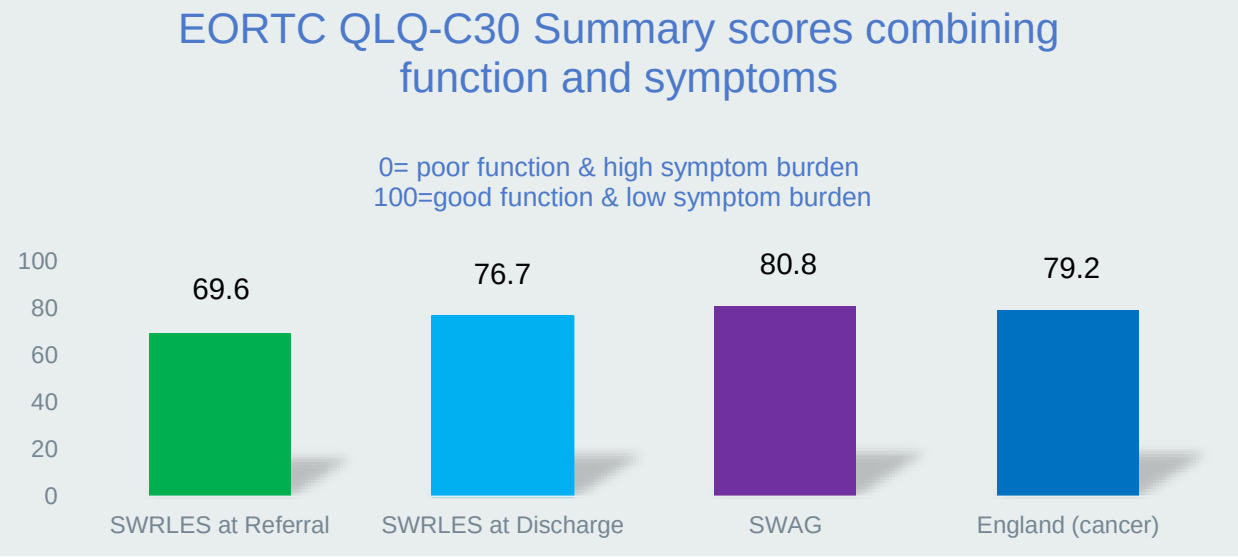


Figure 26: Graph to show summary of QLQ-C30 results



Patient Outcome Summary

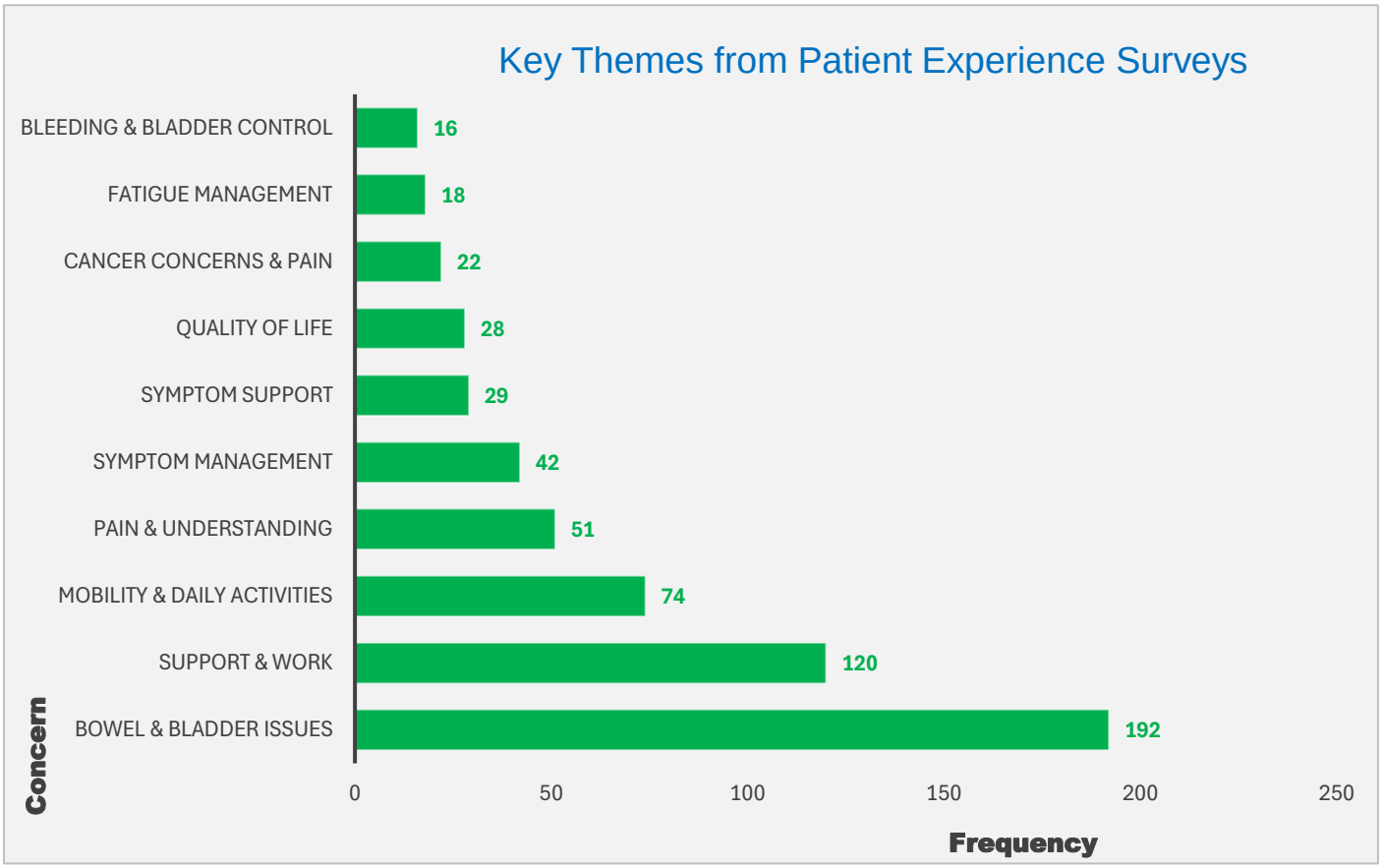
The valuable insights gathered from these survey results are used to guide the development and targeting of interventions aimed at further enhancing patient outcomes and pathways. This evidence demonstrates the effectiveness of the late effects services in bridging the gap between cancer survival and achieving a better quality of life. 70% of all the patients discharged from the SWRLES had an improvement in their overall function and symptoms. 88.2% showed an improvement in QoL from referral to discharge.

8. Patient Experience

"NHS England is committed to ensuring that public and patient voices are at the centre of shaping our healthcare services. Their views should inform service development. This will mean large consultation pieces as well as smaller, more focused sessions developed to listen to individuals, particularly those who do not usually engage in public consultations." [26]

Initially, the SWRLES used the Friends and Family Test (FFT)[27], and "What Matters to You?"[28] to gather patient feedback and understand the concerns of those using the services. The graph below details the range of concerns that people reported:

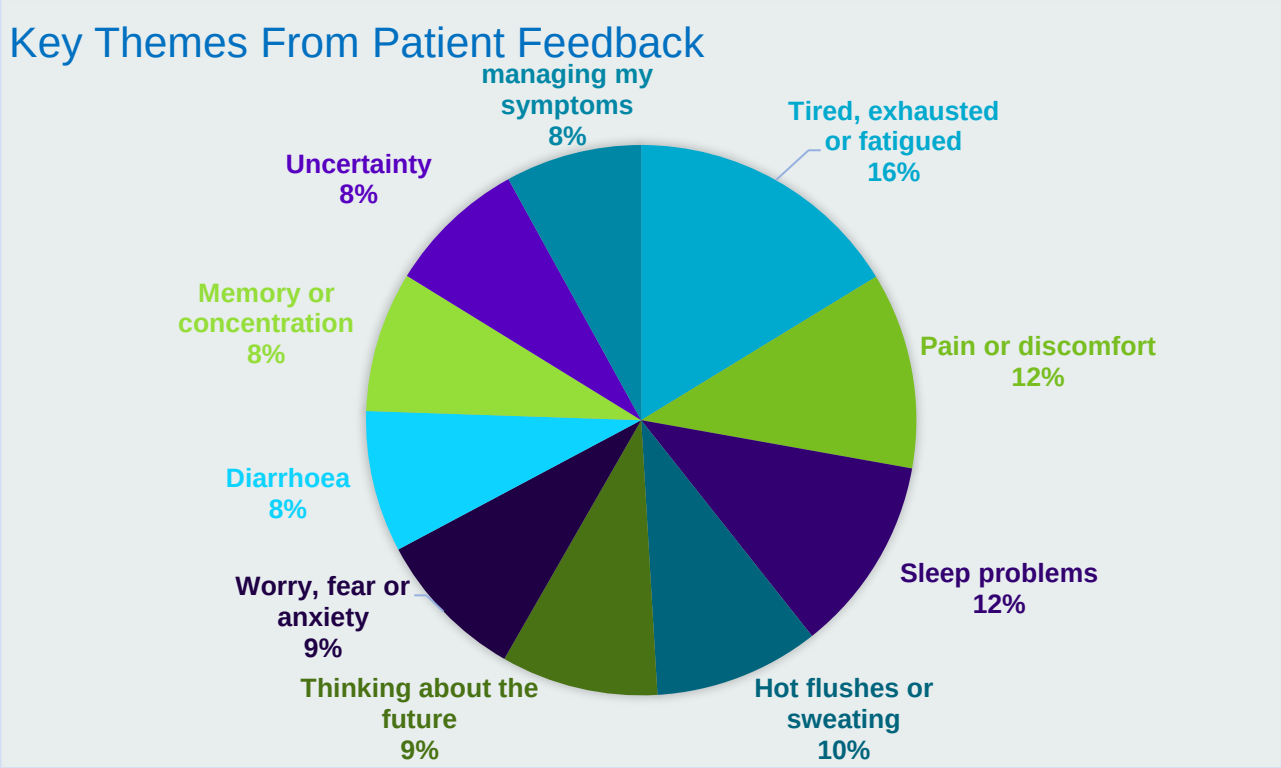
Figure 27: Graph to show feedback themes from patient surveys



[26] bitesize-guide-focus-groups PDF (www.england.nhs.uk)
[27] NHS England » Friends and Family Test data
[28] whatmatterstoyou.

The results were also comparable to the Holistic Needs Assessments (HNAs).[29] completed by SWRLES patients.

Figure 28: Patient survey feedback themes.



Following this initial analysis, the team determined that a comprehensive qualitative investigation would provide deeper insight into the patient experience and effectiveness of the SWRLES. This approach sought to capture personalised patient perspectives on service quality, satisfaction and identify areas for improvement. A diverse focus group was convened, representing various diagnoses, challenges, ages, genders, and ethnic backgrounds. Of 40 invited patients, 10 participated, and were split into two smaller sessions to enable more open discussion. To ensure honest, unbiased feedback, sessions were held off-site, away from the hospital setting, and facilitated by independent project support officers from the local ICB. This neutral environment encouraged candid dialogue, providing a more authentic assessment of patient experiences.

[29] holistic-needs-assessment

Based on the focus group feedback received, several key themes were identified (See Appendix 2 for full details):

- A person-centred approach is critical to meeting individual needs.
- Information is essential for effectively supporting patients.
- There is a clear need to raise awareness about Late Effects services.
- Education should be provided at every stage of the cancer treatment pathway.
- Continuity of care is vital for long-term patient outcomes.
- Late Effect services are highly valuable and wanted by patients, requiring sustained long-term support.

Figure 29: Word map to illustrate key themes from patient focus group.

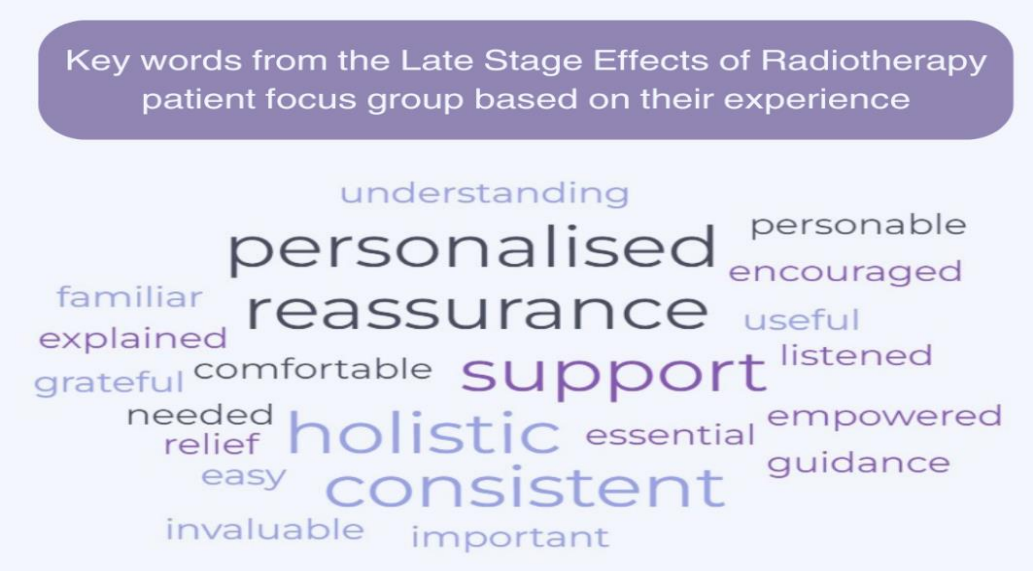
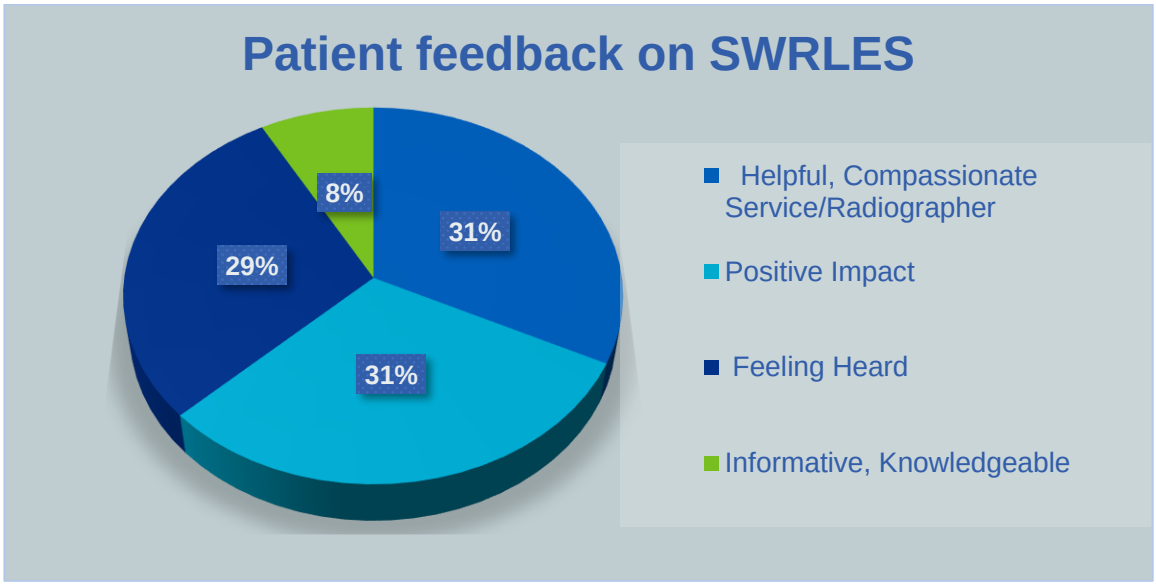


Figure 30: Chart to show patient feedback on SWRLES



Patient Quotes from the focus group in reference to the SWRLES:

"If it was in place earlier it would have saved me so much time and GP appointments."

"Invaluable," "Not alone," "Supportive," "Can't fault it," "Really needed," "Reassuring"

"Got to the bottom of my problems when the GP said it was just depression"

"Support was essential to me recovering and getting through"

"Feel as though I was treated as a person"

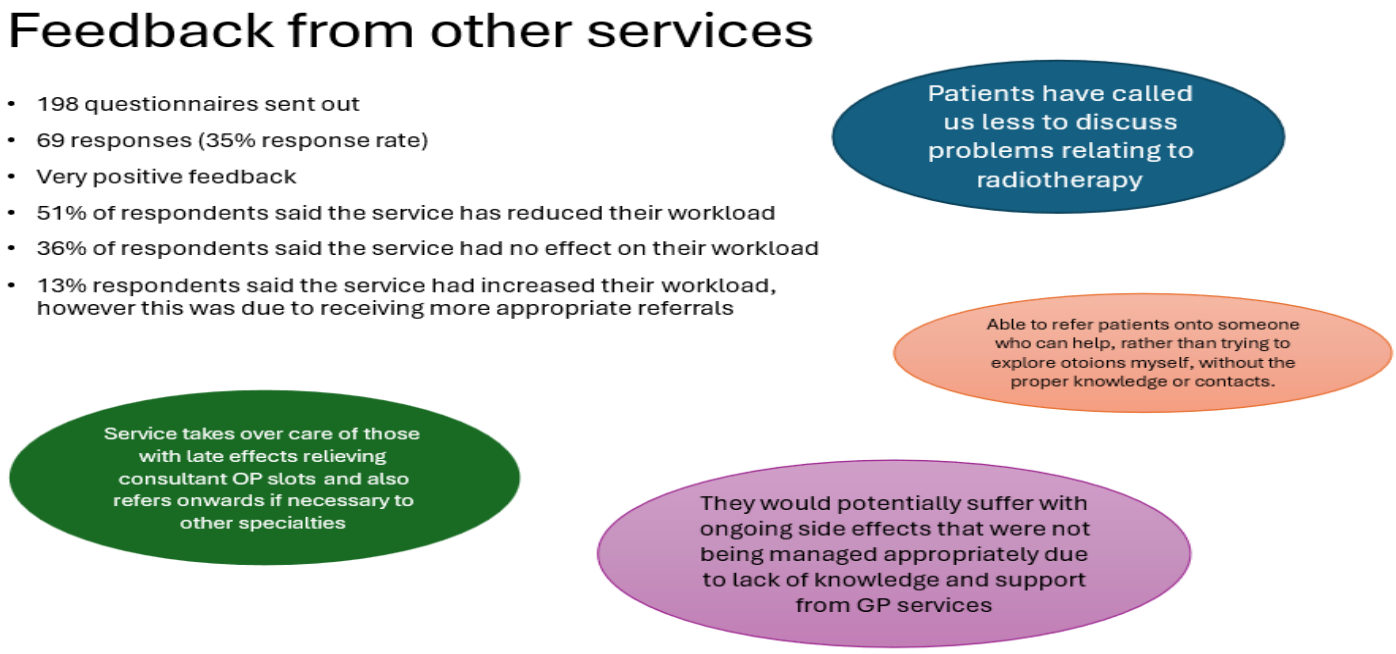
Further patient focus groups are planned. These will be hosted at various times, virtually, and across the whole SWRLES geography in a variety of venues to increase the attendance and provide crucial feedback.

9. Staff Experience

SWRLES surveyed staff across various services to assess its broader impact and effectiveness. Overall, staff value an LES to improve patient care, enhance professional satisfaction, and contribute to a more efficient and sustainable healthcare system:

- Improved Patient Outcomes
- Increased Efficiency & Resource Optimisation
- Enhanced Job Satisfaction
- Strengthened Multidisciplinary Collaboration
- Professional Development & Specialisation
- Services Sustainability

Figure 31: Illustration of key themes from staff survey.



Staff Quotes in reference to the SWRLES:

"The late effects service has centralised the management of problems seen in busy combined oncology clinics so that patients can access timely specialist input for the complications that treatment can cause. The implications of this service not continuing would be that these side effects would go unrecognised, incompletely assessed, inappropriately treated in non-evidenced based ways and ultimately this would cause more work whilst simultaneously bottlenecking consultant led oncology follow up clinics leading to inefficiency. These patients need to see the right person in the right place and for the right amount of time and this is what the late effects services provide. "
Consultant Gynaecological Oncologist 2025 (see Appendix 3 for further staff feedback.)

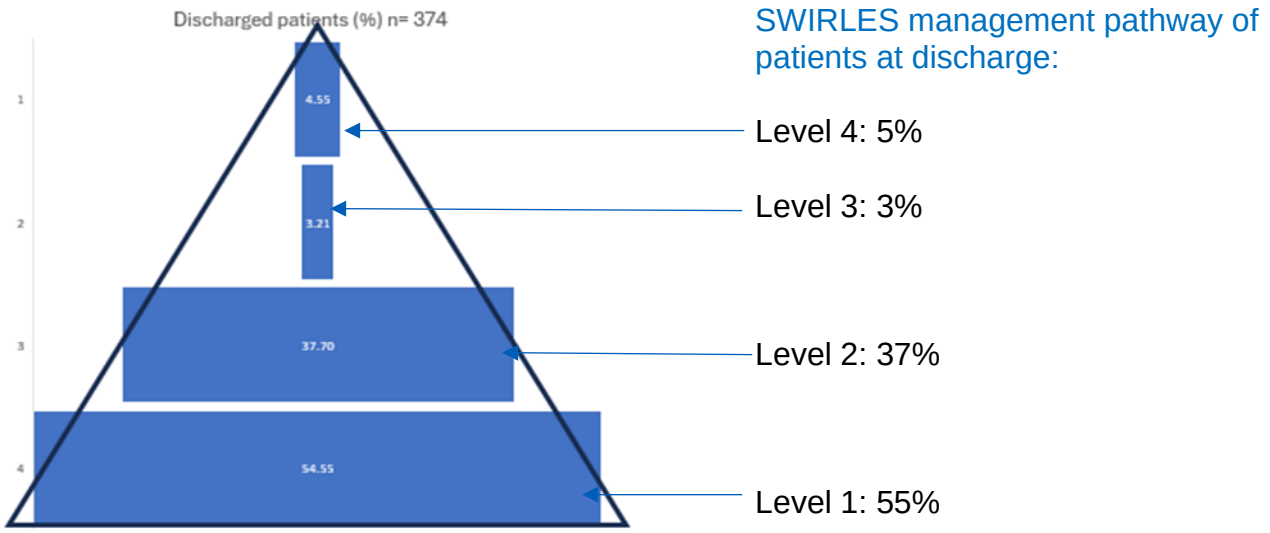
10. Regional Service Model Evaluation

As described previously, the regional service aim was to follow the guidelines set by the NHS Comprehensive Model for Personalised Care. This model prioritises empowering patients to actively manage their care, including the management of late effects from cancer treatment.

The SWRLES provides appropriate access to specialised oncology expertise and support for late effects, ensuring local comprehensive care wherever possible. The objective is to establish a continuum of care that addresses the multifaceted physical, emotional, and psychological ramifications of cancer and its treatment, thereby improving the overall health-related quality of life for all patients.

Current Services Data: As of July 2024, 55% of SWRLES patients were managed and discharged without necessitating further referrals. This data underscores the efficacy and effectiveness of the radiographer-led approach in autonomous patient management, optimising resource allocation within the regional healthcare delivery system, and providing ongoing extensive support for managing late effects of cancer treatment.

Figure 32: Current SWRLES patient management data



11. Southwest Radiotherapy Late Effects Services Evaluation Summary

Value	Category	Measure	Evidence
Is a RLES necessary & efficient?	**Patient usage of Services**	• SWRLES patient numbers exceeded expectation over the pilot period demonstrating a healthcare burden.	• **1306** referrals since services started (2022) • Broad range of late effect symptoms reported
Is a RLES model effective?	**Improved Patient Outcomes/ Management**	• Patients have been discharged from the services demonstrating effective late effects management.	• **791** patients discharged from services since started (2022).
	Enhanced Quality of Life	• Positive patient-reported outcomes with meaningful improvements in QoL.	• **88.2%** of patients report an improvement at discharge
	Financial	• Patients managed as defined by proposed service model. • Reduced utilisation of secondary care OP services.	• **55%** of patients managed by Therapeutic Radiographers • Potential OP cost avoidance of **£96,914** since started • Increase in clinic capacity and specialty utilisation
		• Decreased non-elective admissions	• 640 less NE-admissions resulting in potential cost avoidance of **£774,602** across all cancer types since started
		• Efficient redirection to appropriate and cost-effective services, such as physiotherapy.	• Breast surgery OP specialty usage significantly reduced but physiotherapy usage increased appropriately
Do patients and service providers value a RLES?	**Patients**	• Encouraging, life changing survey and focus group feedback.	• **99%** patient feedback reported positive impact from services
	Staff	• Staff feedback; Potential for improved staff satisfaction, recruitment, and retention	• Wider service feedback suggest burden not being increased elsewhere. • 51% said it reduced workload

12. Conclusion

This service evaluation aimed to assess the impact of the SWRLES and provide evidence to support its ongoing funding after the conclusion of the current Macmillan pilot funding period [March 2025]. The qualitative and quantitative data collected and analysed demonstrate that the SWRLES delivers substantial benefits to meet national recommendations for the management of late effects and improve the outcomes and experiences for the patient and staff.

Healthcare utilisation analysis demonstrates substantial cost avoidance, with reductions in outpatient visits, non-elective admissions, and ED attendances. Since its inception, Somerset RLES has potentially saved approximately £774,000 in non-elective admissions alone, reinforcing its financial and clinical value. Early referral however is crucial in mitigating acute care needs and enhancing patient outcomes.

The significant financial cost avoidance observed in outpatient attendances, non-elective admissions, and ED visits underscore the importance of sustained investment in RLESs. Furthermore, the reduction in non-elective admissions demonstrates operational advantages, including improved patient flow and enhanced waiting-list management, which benefit both patients and the broader healthcare system.

Radiotherapy late effects significantly impact cancer survivors' quality of life, necessitating ongoing support. The Quality-of-Life Survey (QOLS) and patient-reported outcome measures highlight the importance of continuous monitoring to improve care. While RLES have led to notable quality-of-life improvements, challenges remain, emphasising the need for sustained intervention.

The Southwest Radiotherapy Late Effects Services (SWRLES) has shown a transformative impact, integrating therapeutic radiographers to provide holistic care while reducing secondary care dependency. Its expansion, supported by Macmillan Cancer Support and the SWAG Cancer Alliance, offers a scalable model for managing radiotherapy late effects regionally.

Continued investment in SWRLES is essential for equitable access, economic sustainability, and improved long-term care for cancer survivors. Strengthening these services aligns with the

NHS's vision for personalised local cancer care and ensuring better outcomes for patients surviving cancer.

Importantly, the SWRLES plays a critical role in enabling individuals to transition from surviving cancer to living well with and beyond it.

13. Recommendations

The 2024 Lord Darzi Report, *Independent Investigation of the National Health Service in England*[30], evaluates the NHS and proposes reforms. The report emphasises the necessity for enhanced funding and a comprehensive national healthcare dialogue to sustain the effectiveness of the NHS.

In response, the 2025 Government have pledged a comprehensive 10-year reform plan to include:

- **Community and Preventive Care**
- **Digital Transformation**
- **Workforce Expansion**
- **Capital Investment**

Considering these ongoing changes in healthcare policy and infrastructure, it is essential that the SWRLES framework aligns with current and proposed healthcare reforms. The evaluation's recommendations consider these key factors.

SWRLES to be fully commissioned and supported by Trusts to be part of the permanent radiotherapy establishment
• Continued investment in SWRLES is vital for equitable access, economic sustainability, and enhanced long-term care for cancer survivors. • Strengthening these services supports the NHS's vision for personalised, local cancer care, improving outcomes and quality of life for a growing cancer survivor population. • Crucially, it ensures ongoing, effective symptom management for existing patients within the services. Where would these patients be managed if no SWRLES.

[30] https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england?

Explore elements of the SWRLES pathways that could move from hospitals to communities

- Enhancing pathways aligns with the government's vision for a future-ready NHS and treating patient closer to home and in the community.
- Further analysis of local services could demonstrate how secondary care cost avoidance supports managing the rising cancer patient load.
- This would optimise capacity benefits and improve patient outcomes on a broader scale.

SWRLES Utilisation of digital technology

There are potential opportunities to develop the SWRLES to use digital technologies:

- Online surveys (PROMS, electronic Holistic Needs Assessments (eHNAs)
- Automated data collection
- Dashboards for improved analysis of service data and outcomes
- Access to shared care records and Electronic Patient Record (EPR).
- Access to primary care systems.

A permanent RLES would support prevention of ill-health (late effects)

- Enhancing awareness of radiotherapy late effects could facilitate earlier referrals to the RLES, preventing complications that may require costly regional or national services.
- Emerging evidence should be explored to determine whether certain late effects can be mitigated through treatment adjustments or early RLES interventions.
- Strengthening this evidence base would further demonstrate the RLES's value, and benefits both to patients and the healthcare system.

A permanent RLES would continue to share practice, utilise learning and develop national equitable services

- Explore and develop how this award-winning, innovative service could serve as a cost-effective model for nationwide replication, ensuring equitable access to late effects care for all radiotherapy patients.

Explore further analysis into SWRLES and economic impact on primary health care
• Analysing primary care data remains challenging but would be a valuable area for future exploration. • Many patients have frequent GP appointments for issues linked to radiotherapy late effects. • Evaluating how earlier referral to an LES could reduce primary care utilisation and its financial impact would provide critical insights into further service efficiency and cost-effectiveness.

14. Appendices

Appendix 1: Illustrates dashboard created and used for healthcare utilisation.

HRG Chapter: Cancer Site: ALL; Age at Diagnosis: ALL: Age at LES Referral: ALL: ICB: ALL	Non-Elective Admissions Before LES	Non-Elective Admissions per 1000 'Days at Risk'	Non-Elective Admissions After LES	Non-Elective Admissions per 1000 'Days at Risk'	compare before/after LES	rate comparison factor	Non-Elective Admissions 'saved'	Non-Elective Admission Costs 'saved'	Estimated Non-Elective Admissions 'saved' during 2023	Estimated Non-Elective Admission Costs 'saved' during 2023	
Digestive System	67	0.25	67	0.14	more common before LES	1.8	51	£113,011	12	£27,669	After LES significantly lower
Infectious Diseases, Immune System Disorders and Other Hea	85	0.32	43	0.09	more common before LES	3.5	106	£250,991	26	£61,452	After LES significantly lower
Cardiac	58	0.22	42	0.09	more common before LES	2.4	60	£134,201	15	£32,857	After LES significantly lower
Respiratory System	42	0.16	37	0.08	more common before LES	2.0	37	£84,183	9	£20,611	After LES significantly lower
Musculoskeletal System	29	0.11	47	0.10	more common before LES	1.1	4	£12,236	1	£2,996	After LES significantly lower
Urinary Tract and Male Reproductive System	28	0.11	25	0.05	more common before LES	2.0	24	£56,970	6	£13,948	After LES significantly lower
Nervous System	11	0.04	36	0.08	less common before LES	0.5	-17	-£49,214	-4	-£12,049	After LES significantly higher
Skin, Breast and Burns	21	0.08	10	0.02	more common before LES	3.7	27	£57,612	6.6	£14,106	After LES significantly lower
Haematology, Chemotherapy, Radiotherapy and Specialist Pa	17	0.06	14	0.03	more common before LES	2.1	16	£23,548	4	£5,765	After LES significantly lower
Ear, Nose, Mouth, Throat, Head, Neck and Dental	17	0.06	8	0.02	more common before LES	3.7	22	£35,660	5	£8,731	After LES significantly lower
Hepatobiliary and Pancreatic System	10	0.04	7	0.02	more common before LES	2.5	11	£33,162	3	£8,119	After LES significantly lower
Endocrine and Metabolic System	4	0.02	13	0.03	less common before LES	0.5	-6	-£13,375	-1	-£3,275	After LES significantly higher
Undefined Groups	1	0.00	15	0.03	less common before LES	0.1	-13	£0	-3	£0	After LES significantly higher
Vascular Procedures and Disorders and Imaging Interventions	10	0.04	5	0.01	more common before LES	3.5	13	£11,262	3	£2,757	After LES significantly lower
Female Reproductive System and Assisted Reproduction	6	0.02	5	0.01	more common before LES	2.1	6	£16,348	1	£4,003	After LES significantly lower
Multiple Trauma, Emergency Medicine and Rehabilitation	3	0.01	4	0.01	more common before LES	1.3	1	£8,006	0	£1,960	After LES significantly lower
Eyes and Periorbita	0	0.00	5	0.01	less common before LES	0.0	-5	-£9,617	-1	-£2,354	No significant difference
Obstetrics	1	0.00	0	0.00	more common before LES	--	2		0		No significant difference
Diseases of Childhood and Neonates	0	0.00	0	0.00	n/a	--	0		0		No significant difference
Diagnostic Imaging and Nuclear Medicine	0	0.00	0	0.00	n/a	--	0		0		No significant difference
Critical Care and High Cost Drugs	0	0.00	0	0.00	n/a	--	0		0		No significant difference
							337	**£764,985**	**82**	**£187,296**	

HRG Chapter: Cancer Site: ALL; Age at Diagnosis: ALL: Age at LES Referral: ALL: ICB: ALL	A&E Attendances Before LES	A&E Attendances per 1000 'Days at Risk'	A&E Attendances After LES	A&E Attendances per 1000 'Days at Risk'	compare before/after LES	rate comparison factor	A&E Attendances 'saved'	A&E Attendance Costs 'saved'	Estimated A&E Attendances 'saved' during 2023	Estimated A&E Attendance Costs 'saved' during 2023	
Emergency Medicine, No Investigation with No Significant Treatment	27	0.10	34	0.07	more common before LES	1.4	13	£974	3	£239	After LES significantly lower
No investigation with no significant treatment	27	0.10	34	0.07	more common before LES	1.4	13	£756	3	£185	After LES significantly lower
Category 2 investigation with category 1 treatment	29	0.11	28	0.06	more common before LES	1.8	23	£2,518	6	£617	After LES significantly lower
Emergency Medicine, Category 2 Investigation with Category 1 Treatment	29	0.11	28	0.06	more common before LES	1.8	23	£3,436	6	£841	After LES significantly lower
Category 2 investigation with category 4 treatment	14	0.05	27	0.06	less common before LES	0.9	-2	-£343	-1	-£84	After LES significantly higher
Emergency Medicine, Category 2 Investigation with Category 4 Treatment	14	0.05	27	0.06	less common before LES	0.9	-2	-£567	-1	-£139	After LES significantly higher
Category 1 investigation with category 1-2 treatment	19	0.07	19	0.04	more common before LES	1.8	14	£1,122	4	£275	After LES significantly lower
Emergency Medicine, Category 1 Investigation with Category 1-2 Treatment	19	0.07	19	0.04	more common before LES	1.8	14	£1,533	3.5	£375	After LES significantly lower
Category 1 investigation with category 3-4 treatment	6	0.02	5	0.01	more common before LES	2.1	6	£532	1	£130	After LES significantly lower
Category 3 investigation with category 1-3 treatment	5	0.02	6	0.01	more common before LES	1.5	3	£444	1	£109	After LES significantly lower
Category 3 investigation with category 4 treatment	0	0.00	11	0.02	less common before LES	0.0	-11	-£2,365	-3	-£579	No significant difference
Emergency Medicine, Category 1 Investigation with Category 3-4 Treatment	6	0.02	5	0.01	more common before LES	2.1	6	£781	1	£191	After LES significantly lower
Emergency Medicine, Category 3 Investigation with Category 1-3 Treatment	5	0.02	6	0.01	more common before LES	1.5	3	£692	1	£169	After LES significantly lower
Emergency Medicine, Category 3 Investigation with Category 4 Treatment	0	0.00	11	0.02	less common before LES	0.0	-11	-£3,713	-3	-£909	No significant difference
Category 2 investigation with category 2 treatment	3	0.01	2	0.00	more common before LES	2.6	3	£381	1	£93	After LES significantly lower
Emergency Medicine, Category 2 Investigation with Category 2 Treatment	3	0.01	2	0.00	more common before LES	2.6	3	£530	1	£130	After LES significantly lower
Category 2 investigation with category 3 treatment	1	0.00	1	0.00	more common before LES	1.8	1	£102	0	£25	After LES significantly lower
Emergency Medicine, Category 2 Investigation with Category 3 Treatment	1	0.00	1	0.00	more common before LES	1.8	1	£142	0	£35	After LES significantly lower
							99	**£6,957**	**24**	**£1,703**	

Appendix 2: Data collection from patient focus group.

Question	Answers
Question 1: *How did you find your experience of the service?* *Think about your first appointment. Discuss Pro's Con's, would you travel further, be happy with telephone appointments.* *Think about how the service could work if it was virtual or would it not work?*	• Face to face preferred • Don't like telephone • Liked idea of video link • Important to keep to time • Time is valuable and appreciated • Great having 1:1 support • Helpful in making connections • Need for more pathways • Would have travelled the country to get to my first appointment. • Invaluable to meet a person who has professional insight to my experiences • Around this all patients expressed frustration with GP's who continually fobbed them off by dealing with singular issues – not joining the dots or not having the knowledge. • Sometimes patients felt they were being diagnosed with the usual depression as a cover all for GP's lack of knowledge. • Need to raise awareness of service, most came across service accidentally/saw in media • Provided advocacy • Person centred
Question 2: *Any appointments, not just late effects appointments, you have had at the NHS how have you received supporting information?* *For bowel/bladder, eating/drinking, sexual function advice etc-leaflets videos, signposted to websites, how would you like to receive it?*	• At time of treatment decision making, patients felt professionals were unskilled/unwilling or unable to discuss long term side effects. • No radiographers involved in Oncology appointments. • This did not support any in-depth radiotherapy conversations which patients felt would have supported treatment decision making. • Good honest information right at the beginning in leaflet/or video form • Most liked leaflets, due to the ease of accessibility • Leaflets supported by videos also good if they have continuity/further in-depth explanations • Could information be personalised on NHS App • All agreed that it is not only important for patients to have information on late effects and where to get support, but also for clinician education and awareness to be improved. • Need more radiotherapy input in oncology clinics • Empower Therapeutic Radiographers • Lack of knowledge/info given by clinicians • Lack of info about choices • Honest information, freely available/in waiting rooms • Need for greater interprofessional working/joined up care • Hard having to repeat issues at each appointment • Continuity of care build relationships and trust

Further open comments	• Very positive session with some great people and great feedback about how important the late effects clinic is. • For me it has been life changing and meeting with you has helped me to make many changes in my life and feel completely differently from joining the swimming group to focusing on my breathing, pain management and especially speaking with the psychologist to process my feelings and look forward. • Knowing you're there to help if I need it is also a really great source of support, and your name often comes up at the We Get It support group, and we are spreading the word of what you offer and this fantastic service. • Do you have health economist? It would show cost effectiveness of seeing a late effects team saving money. Rather than seeing lots of disciplines that may not understand radiation damage. • Social media app, and campaign for patients to access servers. We all know there are many hidden patients out there.

Appendix 3: Staff feedback on SWRLES.

"I have an excellent working relationship with the Late Effects Service, and it has led to rapid access for patients in regard to treatments, support and access to endoscopy, GI input and collaborations on research projects such as use of Purastat for radiation proctopathy. We have generated pathways for long term management for patients with radiation induced enteritis, bile acid malabsorption, rectal bleeding, defaecatory disorders and incontinence. It would be a great detriment to our patients, our primary care colleagues and the Trust if a service like this not given on going funding. This type of forward thinking, collaborative, clinical approach across different departments, is what the future of the NHS aspires to. I have no hesitation whatsoever, in offering my full support. "
Consultant Gastroenterologist 2025.

"I have been asked to comment on our findings /user experience from the late effects service locally.
Last summer the breast service education day included a talk by the late effects team which was extremely helpful and well received. Since then, the surgical part of the service has been much more aware of the benefits provided and have found the service to be invaluable. It can be very difficult in a diagnostic service to know what to do, and who to ask with treatment related side effects, and this service is really a game changer. We really hope it can continue, as it could save a lot of extra consultations and symptoms/patient anxiety in the long term. "
Clinical Lead for Breast Surgery Services 2025

"I cannot say enough good things about the Late Effects Service. It is invaluable to our patients and is often the only place that can help them manage long term sequelae of breast cancer treatment. Without exception, the patients that I have referred there have benefitted from the time and care and advice that they are given. There is no other equivalent service/charity that these long-term patients can get this sort of input, and we would be lost without it. "
Consultant Breast Surgeon. 2025

"We are so grateful to the Radiotherapy Late side effects team for supporting our patients who can experience complex and varying side effects from their radiotherapy. While many of our patients experience minor effects from their treatment some, unfortunately, can be left with issues such as (to name a few), chronic pain, nerve damage, shortness of breath, and fatigue. Sometimes these side effects can be debilitating and have a significant impact on breast cancer survivors' quality of life. The Late effects team are essential to us by being able to holistically assess these side effects and make suggestions and recommendations based on their extensive experience and knowledge.

"We aim to cure our patient's cancer and stop it from returning, but sadly some people are left with side effects that can be life changing. There is no other service that addresses these issues, and our patients would be very much worse off without it. "
Senior Breast Nurse Specialist 2025.