

SCHEDULE 2 – THE SERVICES

A. Service Specifications

1. Service name	Pain-related Complex Cancer Late Effects Rehabilitation Service (CCLERS)
2. Service specification number	B01/S(HSS)a – 241203S
3. Date published	December 2024
4. Accountable Commissioner	NHS England » Cancer HSS

5.	Population and/or geography to be served
5.1	Population Covered Adults
5.2	Minimum population size Not Used
6.	Service aims and outcomes
6.1	<p>Service aims</p> <p>This service specification describes the provision of the Complex Cancer Late Effects Rehabilitation Service (CCLERS) including the Breast Radiotherapy Injury Rehabilitation Service (BRIRS).</p> <p>CCLERS is for a discrete group of service-users who have severe, chronic and complex conditions resulting from their cancer treatment. CCLERS provides the highest quality of assessment and rehabilitation for service-users with reduced function caused by complex pain-related late effects from cancer treatment.</p> <p>CCLERS draws on an interdisciplinary approach to offer tailored, specialist functional rehabilitation programmes, utilising multi-sensory neurocognitive techniques and hydrotherapy. This approach differentiates CCLERS programmes from more generalist pain interventional clinics and psychology-based pain management programmes.</p> <p>Treatment-related late effects pain often does not occur in isolation, there may be other symptoms and problems requiring input from a wide range of local and regional specialisms, including speech and language therapy, nutrition, urology, neurology, psychosexual services etc. CCLERS identifies and provides support to manage some of these symptoms where appropriate, and also refers/signposts to regional centres, when necessary, often supporting service-users to negotiate and engage with these services in follow up.</p>

CCLERS enables the service-users affected to minimise the impact of late effects cancer pain on their lives and improve their function and quality of life.

CCLERS aims to:

- Optimise clinical outcomes and deliver appropriate bespoke highly-specialist care for this population.
- Bring together a highly-specialist multi-disciplinary team who have a clear understanding of the healthcare needs associated with pain-related late effects.
- Act as a direct source of advice and support both to other healthcare professionals and service-users when they contact or refer into the service.
- Provide education within the wider NHS to raise and maintain awareness of pain-related cancer late effects and their management.
- Participate in networking and continuous professional development.
- Expand clinical expertise that will generate new knowledge of the course, cause, and treatment of these effects in order to inform future cancer care.

NHS Outcomes Framework Domains

Preventing people from dying prematurely

CCLERS specialist interventions and timely signposting to appropriate primary and secondary care services supports service-users' complex health needs and can reduce the risk of premature mortality.

Enhancing quality of life for people with long-term conditions

Living with pain-related late effects is a long-term condition. CCLERS has demonstrated improvements in depression severity, anxiety, perceptions of pain interference and function. CCLERS interventions include collaboration on goals identified by the service-user and interdisciplinary input.

Helping people to recover from episodes of ill-health or following injury

CCLERS provides proactive education and self-management advice with signposting to help patients stay as healthy as possible and improve strength and function to prevent episodes of ill health or injury.

Ensuring people have a positive experience of care

CCLERS undertakes ongoing qualitative assessment to evaluate the experience of care. Patient feedback is obtained following MDT Assessment Clinics and at the three and twelve-month review. Patients are invited to complete a patient experience questionnaire post the rehabilitation programme.

	<p>Treating and caring for people in safe environment and protecting them from avoidable harm</p> <p>Staff adhere to NHS and local Trust policies and complete mandatory training. Procedures are in place for suicide risk assessment. CCLERS provides clean, safe accommodation with careful risk assessments pre-treatment and a safe treatment environment with protection from avoidable harm.</p>										
<p>6.2</p>	<p>Outcomes</p> <p><u>NHS Outcomes Framework Domains & Indicators</u></p> <table border="1" data-bbox="263 698 1410 1003"> <tr> <td>Domain 1</td> <td>Preventing people from dying prematurely</td> </tr> <tr> <td>Domain 2</td> <td>Enhancing quality of life for people with long-term conditions</td> </tr> <tr> <td>Domain 3</td> <td>Helping people to recover from episodes of ill-health or following injury</td> </tr> <tr> <td>Domain 4</td> <td>Ensuring people have a positive experience of care</td> </tr> <tr> <td>Domain 5</td> <td>Treating and caring for people in safe environment and protecting them from avoidable harm</td> </tr> </table> <p><u>Service defined outcomes</u></p> <p>CCLERS measures clinical outcomes at baseline (post triage) and at three and twelve months post the intervention (the CCLERS rehabilitation programme).</p> <p>Outcomes include:</p> <ul style="list-style-type: none"> - reduction of the impact and severity of pain - reduction in fear of movement - improvement in daily function - improvement in mood, including anxiety and depression severity <p>CCLERS uses the following outcome measurement tools:</p> <ul style="list-style-type: none"> - the Brief Pain Inventory to measure the impact and severity of pain - (two domains) - the Tampa Scale of Kinesiophobia to evaluate fear of movement - the PROMIS SF20a to assess overall improvement in function - the Patient Health Questionnaire (PHQ-9) to assess for depression severity - the Generalised Anxiety Disorder (GAD-7) to evaluate anxiety levels 	Domain 1	Preventing people from dying prematurely	Domain 2	Enhancing quality of life for people with long-term conditions	Domain 3	Helping people to recover from episodes of ill-health or following injury	Domain 4	Ensuring people have a positive experience of care	Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm
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Reference	Domain	Rationale	Indicator
CCLERS07, 13, 19	3	To understand outcome	Proportion of patients whose BPI Severity score improved after intervention, 3 and 12 months compared with baseline score
CCLERS08, 14, 20	3	To understand outcome	Proportion of patients whose BPI pain interference with function score improved after intervention, 3 and 12 months compared with baseline score
CCLERS09, 15, 21	3	To understand outcome	Proportion of patients whose GAD-7 score improved after intervention, 3 and 12 months compared with baseline score
CCLERS10, 16, 22	3	To understand outcome	Proportion of patients whose PHQ -9 score improved after intervention, 3 and 12 months compared with baseline score
CCLERS11, 17, 23	3	To understand outcome	Proportion of patients whose Tampa Scale of Kinesio phobia score improved after intervention, 3 and 12 months compared with baseline score
CCLERS12, 18, 24	3	To understand outcome	Proportion of patients whose PROMIS SF 20a – functional measure score improved after intervention, 3 and 12 months compared with baseline score

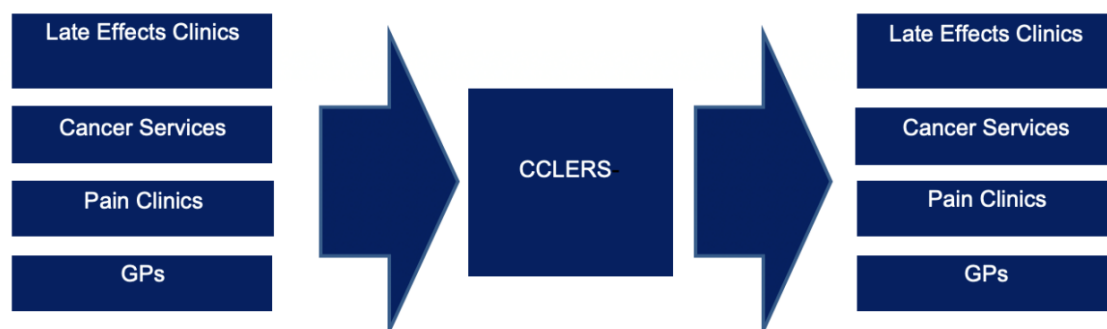
These outcomes will be complemented by qualitative data collection tools used to evaluate the patients' experience of the MDT Assessment Clinic, the Rehabilitation programme and follow up post programme. Patients will also participate in the national outpatient and in-patient surveys.

The full definition of the quality outcomes and metrics together with their descriptions including the numerators, denominators and all relevant guidance will be accessible at <https://www.england.nhs.uk/commissioning/spec-services/npcrg/specdashboards/> following the next scheduled quarterly refresh of the dashboard metadata document.

7.	Service description
7.1	<p>Service model</p> <p>CCLERS provides highly-specialist rehabilitation. The Service develops relationships with patient's referrers and GPs in order to support, advise and share care with services local to where patients live. CCLERS triages, clinics, follow up reviews and virtual programme operate in standard office hours, Monday to Friday 9.00-17.00. The inpatient programme operates 24/7 in two weeks blocks.</p> <p>The CCLERS Service Model provides individualised, inter-disciplinary assessment and rehabilitation tailored to each service-user's needs. The CCLERS pathway</p>

	<p>consists of a telephone triage, multiple specialist assessments in an MDT clinic, possible progression onto an intensive two-week rehabilitation programme, and follow up post programme for a year. The two-week inpatient programme utilises facilities including hydrotherapy and on-site residential accommodation.</p> <p>Alongside face-to-face appointments, CCLERS offers the option of virtual clinic and follow up appointments and in special circumstances, a virtual rehabilitation programme. Approximately 1/2 of patients referred are invited to attend an MDT Assessment Clinic. Approximately 1/3 of patients referred will go on to attend the rehabilitation programme. CCLERS provides a minimum of three MDT Assessment Clinics a year and three rehabilitation programmes.</p> <p>The MDT Assessment includes physiotherapy, occupational therapy, psychology, nursing and medicine. The number of expert staff, with backgrounds in functional pain rehabilitation and cancer care, who can provide the service is very small. Although there is some flexibility within the skill mix, representation from each specialty is a minimum requirement.</p>
7.2	<p>Pathways</p> <p><u>Overall patient pathway</u></p> <p>At a local level across England, there are no clear pathways for people with pain-related cancer late effects to easily access appropriate treatment and care. There is no clear local pathway for service-users with pain-related cancer late effects. The CCLERS cohort find it difficult to access appropriate services because:</p> <ul style="list-style-type: none"> - Service-users may have finished cancer follow up and rehabilitation, as late effects can develop or deteriorate many years after treatment, so are no longer under hospital care. - Local pain and rehabilitation services may not accommodate cancer-related pain conditions within their criteria or have staff equipped to manage this cohort. - There is no consistent approach to the commissioning of Late Effects pathways or clinics locally although there is some provision, for example for specific types of late effects to the exclusion of others, such as gastrointestinal or radiotherapy late effects services which are available in only a small number of locations in England. <p>Awareness of the needs of people with late effects of cancer treatment is increasing within the NHS. To support ease of access CCLERS accepts referrals from any health professional in England, typically, referrals come from Late Effects Clinics, Cancer Services, Pain Clinics and GPs.</p> <p>The referring service may continue to have contact with the service-user while they are receiving input from CCLERS. Service-users are discharged back to their GP,</p>

signposted or referred to other local services or local referring service, if appropriate.



Specialised patient pathway

CCLERS service-user pathway:

1. Referral:

Service-users can be referred into the national service by any health professional. Referral criteria include:

- Severe and persistent pain and reduced function due to the consequences of curative cancer treatment including radiotherapy, chemotherapy, and surgery (any tumour site).
- Already seen by local pain, rehabilitation and/or late effects services without improvement in symptoms.
- Considered highly complex by local/regional services.
- Completed cancer treatment at least 12 months previously (excluding hormone therapy).

A new referral will be validated against GP-held healthcare records to ensure that it meets the service inclusion criteria before acceptance.

2. Clinical Nurse Specialist Telephone Triage:

The triage assessment is a holistic telephone assessment which incorporates previous and current medical problems, pain history, functional status, a brief social and psychological history and service-user expectations from the Service. The completed document is available to all clinicians in the MDT Assessment Clinic.

Following triage, service users will either progress to MDT Assessment Clinic or be referred back to local services as current health needs are already/can be met locally. Service users may also need further investigations, or they might choose not to proceed at this point. In these circumstances, a letter is sent to the GP, referrer and service-user discharging them with any recommendations/signposting identified from the triage.

3. Multi-disciplinary Team (MDT) Assessment Clinic:

Highly-specialist care is provided as a “one stop shop” with individual consultations with a physiotherapist, occupational therapist, psychologist, clinical nurse specialist and pain consultant. Each appointment contains an educational component to help understanding of current symptoms, past experiences, and on-going self-management. Following the MDT Assessment Clinic, each service-user receives a specialist assessment with recommendations and signposting, which is also sent to GP and referrer.

A potential outcome after MDT Assessment Clinic is progression onto a more intensive, individualised, rehabilitation programme. The criteria for the programme are:

- A service user has highly complex rehabilitation needs AND
- Clinical opinion that significant health gains in terms of physical function could be achieved by daily, intensive treatments greater than those from an outpatient course of routine local care (usually therapy one day a week for six weeks)
- Service-users are engaged with the therapy and are open to make changes necessary to improve their function.

Service-users who do not progress to the rehabilitation programme will receive a follow up call at three months post MDT Assessment clinic to check the service-users progress with implementation of recommendations, signposting suggestions and suggested self-management strategies. Any issues will be followed up and local services contacted. This group of service-users will be discharged at this point.

4. Rehabilitation Programme:

The two-week programme provides highly-specialist, interdisciplinary rehabilitation. It has been informed by existing national functional pain rehabilitation programmes and is tailored for the specific needs of CCLERS service-users. The programme typically comprises individualised land-based physiotherapy, hydrotherapy, occupational therapy and psychological therapy (delivered individual and/or in a group). Following the programme, each service-user will agree a tailored personalised care and support plan based on their identified goals, which is copied to the GP and referrer.

5. Follow Up:

On completion of the functional rehabilitation programme, service users are offered a virtual or face to face clinical review by the Therapy Team and Clinical Nurse Specialist at 3 months. Service users are then offered telephone/virtual reviews at 6 and 12 months with the CNS and/or a therapist if required. These reviews advise

and support the service-user goals identified in the rehabilitation programme. Following each review, a letter will be sent to the service user, GP and referrer outlining progress made and any on-going difficulties, with advice and recommendations for care stakeholders.

6. Discharge:

Service-users will be discharged when they have reached 12 months post programme. A letter is sent to the service-user, the referrer and the GP on discharge. Criteria for discharge from CCLERS:

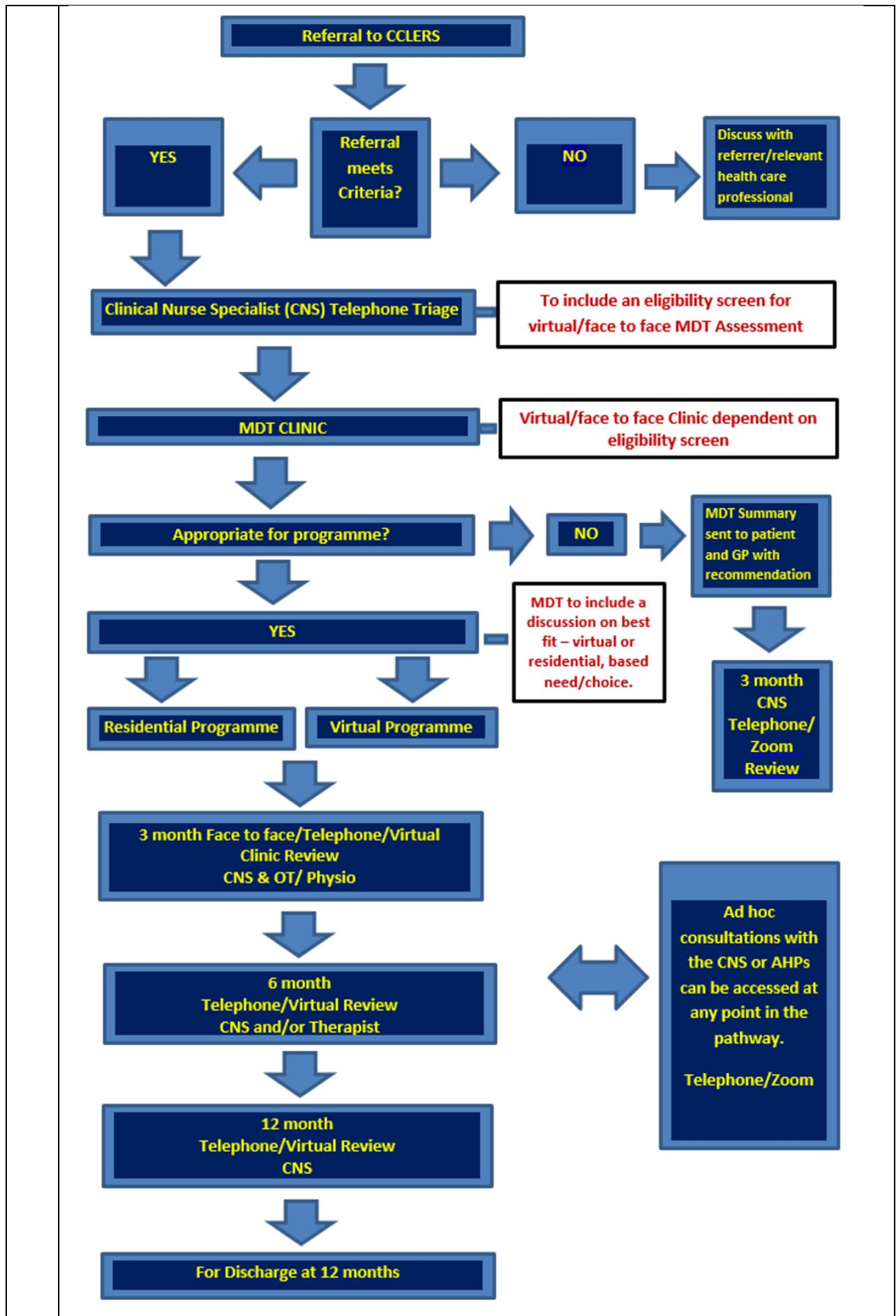
- No further investigation required.
- No adverse outcomes anticipated.
- Clinically appropriate arrangements for local care and follow up are in place.
- Discharge has been discussed and agreed by all parties
- Service-users and carers understand and have the necessary information to contact the CCLERS in the future, if their problems deteriorate again afterwards.

On discharge, service-users will have a tailored self-management plan which they will have been supported to put into place during follow up. They will have been referred/signposted to appropriate local services if necessary and supported to engage with these services. Their needs will have been communicated fully to key stakeholders (their GP and local teams).

Shared care arrangements

CCLERS works closely with referrers and service-users' GPs to provide a direct source of advice and support when service-users are referred into the Service. CCLERS staff form a relationship with local health and social care providers to help to optimise any care provided locally for the service-user. This may include liaison with Consultants, GPs, community nurses or social workers. The CCLERS pathway embeds communication with service-users, referrers and GPs within every episode of care, through to discharge

Part of CCLERS remit as a national service provider is to raise and maintain awareness of pain-related, functional, cancer late effects and their management at a national level within the NHS, acting as a resource and centre of excellence. To facilitate this, CCLERS staff is associated with national and regional clinical networks and services across England to support improved knowledge and understanding of the specialism and to optimise any care provided locally to the patient.



7.3 Clinical Networks

National Programme of Care/ Clinical Reference Group (CRG)	Link to CRG:
Radiotherapy	https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-b/b01/

All Providers are required to participate in a networked model of care to enable services to be delivered as part of a co-ordinated, combined whole system approach. To promote awareness of the Service, to advocate for service users at a local and regional level and to share best practice, CCLERS is affiliated with the following national clinical networks and affiliations:

The Radiographer Late Effects Special Interest Group

<https://www.sor.org/about/get-involved/special-interest-groups/radiotherapy-late-effect-sig>

This group has scoped Radiographer Late Effects Services across England and can facilitate a Step Up/Step Down approach for CCLERS service-users with radiotherapy pain-related effects. Regional variation exists for these Late Effects Clinics, and they focus primarily on radiation damage, while CCLERS supports people with pain-related late effects from all curative cancer treatments.

Macmillan Healthcare Professionals Community of Practice

This is an informal national clinical network which enables CCLERS to connect to local cancer pre/rehabilitation services across England through Macmillan communication links and also contribute to national training packages to increase knowledge and awareness of pain-related late effects.

Informal Cancer Healthcare Professional Networks:

CCLERS provides education to support management of pain-related late effects and rehabilitation to informal networks of healthcare clinicians, often based in regional cancer centres and/or associated with university training for Healthcare professionals. Contacts within Macmillan raise awareness and promote the Service in the Cancer Alliances.

UK Oncology Nursing Society (UKONS) Cancer Pain Working Group

<https://www.ukons.org/members-interest-groups/>

This UKONS national clinical members interest sub-group was formed to raise awareness of cancer pain including late effects pain and its management by health professionals from pain and cancer communities at local, regional, and

	<p>national level. The group brings together academics and provider nursing staff with cancer and pain backgrounds in regional centres across England.</p> <p>National Paediatric Aftercare/Late Effects Network</p> <p>Many childhood cancer survivors have late effects into adulthood but are still under the care of paediatric services. The national paediatric late effects network brings together regional specialist paediatric late effects teams, within which CCLERS can raise awareness of functional pain rehabilitation.</p> <p>Building relationships within these networks and promoting and educating health professionals about the difficulties associated with pain-related late effects, what is needed locally to support service-users within cancer and pain pathways and what CCLERS rehabilitation offers nationally is a key part of CCLERS service provision. This ensures that the Service is supporting primary as well as secondary and tertiary prevention within its scope of practice.</p>
7.4	<p>Essential Staff Groups</p> <p>The following staff groups are essential to the delivery of CCLERS:</p> <ul style="list-style-type: none"> • Specialist Physiotherapist • Specialist Occupational Therapist • Clinical Psychology • Pain Consultant • Clinical Nurse Specialist • Therapy Assistant • Healthcare Assistants • Administrators <p>CCLERS is a therapy and nursing led service offering specialist, interdisciplinary, functional specialist rehabilitation. The composition of the CCLERS MDT is informed by existing national functional pain rehabilitation programmes. Therapy approaches are based on published best practice:</p> <ul style="list-style-type: none"> • Exercise and Chronic Disease, An Evidence-based Approach. Saxton J (ed). Routledge 2011. • Morgan MA (2009) Cancer Survivorship: History, Quality of Life Issues and Evolving Multi-Disciplinary Approach to Implementation of Cancer Survivorship Care Plans. Oncology Nurse Forum. doi: 10.1188/09.ONF.429-436 • Raphael J et al. Cancer Pain: Parts 1&2. Journal of Pain Medicine. doi: 10.1111/j.1526-4637.2010.00840.x • Glare et al (2014) Pain in Cancer Survivors. Journal of Clinical Oncology. https://dx.doi.org/10.1200%2FJCO.2013.52.4629

7.5	<p>Essential equipment and/or facilities</p> <p>The following equipment and facilities are essential for CCLERS delivery:</p> <ul style="list-style-type: none"> • Gym, hydro-pool; OT room, therapy kitchen, service-user rest room; clinic rooms and office space. • Service-user accommodation – 6-8 purpose-built rooms, toilet and washing facilities, a dayroom. • Electric vehicle for transportation between sites. • Walking aids, small hand aids, art and craft materials, kitchen utensils and food, physio gym equipment; office equipment, pool equipment. <p>All CCLERS facilities and equipment should be subject to the governance policies of the trust to ensure upkeep and safe usage.</p>
7.6	<p>Interdependent Service Components – Links with other NHS services</p> <p>Not applicable</p>
7.7	<p>Additional requirements</p> <p>Not applicable</p>
7.8	<p>Commissioned providers</p> <p>Royal United Hospital Bath NHS Foundation Trust.</p>
7.9	<p>Links to other key documents</p> <p>CCLERS must be fully integrated into corporate and clinical governance arrangements. There are currently no specific NICE guidelines for best practice in the management of pain-related cancer late effects classed as secondary chronic pain, however the service must comply with:</p> <p>Chronic pain (primary and secondary) in over 16's: assessment of all chronic pain and management of chronic primary pain (2021) NICE guideline NG193 https://www.nice.org.uk/guidance/ng193</p> <p>Neuropathic pain in adults; pharmacological management in non-specialist settings (2013; Last updated 2020) NICE Guideline CG173. https://www.nice.org.uk/guidance/cg173</p> <p>Medicine adherence (2009) NICE Guideline CG76. https://www.nice.org.uk/guidance/cg76</p>

	<p>Medicines associated with dependence or withdrawal symptoms: safe prescribing and withdrawal management for adults (2022) NICE Guideline NG215 https://www.nice.org.uk/guidance/ng215</p> <p>2021 Surveillance of patient experience in adult NHS services (NICE guideline CG138) (2023) https://www.nice.org.uk/guidance/cg138/resources/2021-surveillance-of-patient-experience-in-adult-nhs-services-nice-guideline-cg138-pdf-11926783529413</p> <p>Core Standards for Pain Management Services in the UK: (2nd Edition) Cancer-related Pain (2021) Bennet and Sharma – p. 88 https://www.britishpainsociety.org/static/uploads/resources/files/FPM-Core-Standards-2021.pdf</p> <p>Pelvic Radiation Disease Best Practice Pathway (2022) PRDA; https://www.prda.org.uk/wp-content/uploads/2022/09/PRDA_Best-Practice-Pathway_Toolkit.pdf</p> <p>Give due regard to other national guidance regarding support for people to live well after cancer treatment, including personalised care and improving quality outcomes (NHS England – Personalised Care and Improving Quality of Life Outcomes) and the implementation of universal personalised care across the NHS (NHS England – Universal Personalised Care: Implementing the Comprehensive Model).</p>
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Change form for published Specifications and Products developed by Clinical Reference Group (CRGs)

Product name: Pain-related Complex Cancer Late Effects Rehabilitation Service (CCLERS)

Publication number: B01/S(HSS)a-241203S

Description of changes required

Describe what was stated in original document	Describe new text in the document	Section/Paragraph to which changes apply	Describe why document change required	Changes made by	Date change made
<p>Spec title: Breast radiotherapy injury rehabilitation service (Adult) https://www.england.nhs.uk/wp-content/uploads/2013/06/b01-breast-radio-rehab.pdf</p>	<p>Spec title: Pain-related Complex Cancer Late Effects Rehabilitation Service (CCLERS)</p>	<p>1</p>	<p>The original specification, adopted in 2013, was the Breast Radiotherapy Injury Rehabilitation Service [BRIRS] (Adult). Following agreement from the Highly Specialised Commissioning Team, BRIRS has transitioned over the past few years from managing a narrower cohort of patients with breast radiotherapy injury. The number of patients in the BRIRS cohort has reduced (as cancer treatments have become safer and more targeted), while treatment-related pain associated with other tumour sites (pelvis and head and neck cancers) became more well-known and understood. After a successful</p>	<p>HSS Team</p>	<p>16/10/23</p>

			pilot in 2016-17, BRIRS began accepting referrals related to any tumour site. The amendments to the specification reflect the highly specialised service being provided.		
Service aims and pathway for the assessment and rehabilitation for women and men with Radiation Induced Auxiliary Tunnel Damage	Service aims and pathway for the assessment and rehabilitation for service-users with reduced function caused by complex pain-related late effects from cancer treatment.	6.1	See above. The published service spec does describe a service aim to build knowledge to optimise clinical outcomes in other late effects.	HSS Team	16/10/23
Outcomes <ul style="list-style-type: none"> • improvement in pain management; • improvement in daily function; • improvement in Quality of Life 	Outcomes are broadly similar but have been updated in collaboration with QNT with time intervals and measurements being specified	6.2		QNT	17/12/23
The service model describes satellites units in Barts and at the Christie with MDT assessment and treatment conducted	The revised specification describes a service commissioned only at Bath offering the similar model	7.1	Commissioning of satellite centres ceased some years ago; the service is now commissioned only at the Royal United Hospitals Bath.	HSS Team	16/10/23

across hub and satellite units; highly specialist inpatient rehabilitation will only be offered at the designated hub based at RNHRD.	individualised, inter-disciplinary assessment and inpatient rehabilitation tailored to each service-user's needs including use of virtual access.				
Location of providers • The Royal National Hospital for Rheumatic Diseases NHS Foundation Trust, Bath • Barts Health NHS Trust, London • The Christie Hospital NHS Foundation Trust, Manchester	Location of providers • Royal United Hospital Bath NHS Foundation Trust	7.8	Providers changed.	HSS Team	16/10/23
3.1 Applicable national standards	7.9 Links to other key documents updated	7.9	Original standards and links now out of date.	HSS Team	16/10/23
Old service specification template, spec written prior to 2013 and adopted	Specification written into the new template, so some refreshing of specification and information mapped into new sections.		Need to update into new template	HSS Team	16/10/23