

Healthy London
Partnership



Mapping of pan London cancer rehabilitation services

Transforming Cancer Services Team

July 2019

MACMILLAN
CANCER SUPPORT

About Healthy London Partnership

Healthy London Partnership formed in 2015. Our aim is to make London the healthiest global city by working with partners to improve Londoners' health and wellbeing so everyone can live healthier lives.

Our partners are many and include London's NHS in London (Clinical Commissioning Groups, Health Education England, NHS England, NHS Digital, NHS Improvement, trusts and providers), the Greater London Authority, the Mayor of London, Public Health England and London Councils.

All our work is founded on common goals set out in [Better Health for London](#), [NHS Five Year Forward View](#) and the [Devolution Agreement](#).

About the Transforming Cancer Services Team (TCST)

The Transforming Cancer Services Team is part of the Healthy London Partnership. The Transforming Cancer Services programme was established April 2014 to provide strategic leadership, clinical advice, oversight, cohesion and guidance for implementing the National Cancer Strategy for London. The programme aims to improve outcomes for patients through a pan London clinically-led, patient-centred collaborative approach.

Our **vision** is for all Londoners to have access to world class care before and after a cancer diagnosis.

Our **mission** as a trusted partner is to drive delivery of world class cancer outcomes through collaboration, commissioning support, clinical leadership, education and engagement.

About this document

The purpose of this report is to present findings from a comprehensive mapping exercise of adult cancer rehabilitation services in London and West Essex, and to make recommendations for the provision and development of services in the region. This report is one of three work stream reports which developed from the Transforming Cancer Services Team (TCST) scoping report published in February 2017. The findings of this report will also be included in the TCST Commissioning Guidance for Cancer Rehabilitation due for publication later in July 2019.

Disclaimer

The information collected in this document was collected from Monday, 12 February 2018 – June 2018 and December 2018 – January 2019 (the break in data collection due to changes in staffing). The information provided was correct at the time of publication and was ratified in March 2019.

This report was funded by Macmillan Cancer Support

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk To give, fundraise or volunteer call 0300 1000 200 or visit macmillan.org.uk

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Executive Summary

The purpose of this report is to present findings from a comprehensive mapping exercise of adult cancer rehabilitation services in London and West Essex, and to make recommendations for the provision and development of services in the region. This report is one of three work stream reports which developed from the Transforming Cancer Services Team (TCST) [scoping report](#) published in February 2017. The other two publications are:

- [Cancer Rehabilitation Data Recommendation Report](#) (published October 2017)
- [Cancer Rehabilitation Service Improvement Tools](#) (published December 2018)

The findings of each of these reports will also be included as part of the TCST Commissioning Guidance for Cancer Rehabilitation due for publication later in July 2019.

Methodology

A multi-disciplinary task and finish group supported The Transforming Cancer Services Team (TCST) to carry out this work. For the purpose of this report, cancer rehabilitation services were defined as those providing the services outlined below, with the objective of managing the consequences of cancer and cancer treatment:

- Physiotherapy
- Occupational therapy
- Speech and language therapy
- Nutrition and Dietetics
- Physical activity programmes

Only services with a direct referral route for cancer patients were included. Lymphoedema services and workforce intelligence were not included in this report, as these services have been mapped previously and will be refreshed in Autumn 2019.

To conduct this mapping exercise, two surveys were developed in collaboration with key stakeholders, to target both service providers and commissioners. The surveys aimed to capture data around:

- Overview of service provision
- Location
- Access
- How the service is commissioned
- Evaluation and quality assurance of the service

The surveys were disseminated via a snowball approach, identifying key leads within services and commissioning. This methodology was supported with desk research and quality assurance through key leads in the region.

Key highlights

- Acute provision of cancer rehabilitation is relatively well spread; five STPs have specific provision for physiotherapy, occupational therapy, dietetics and speech and language therapy. West Essex has non-cancer specialist rehabilitation services. The extent of provision is variable with certain trusts providing a significant volume of cancer services, for example at Barts Health NHS Trust, The Royal Marsden NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust.
- There are significant gaps in access to cancer rehabilitation. For example, many services are only available for patients with certain tumour types and at certain points of the pathway.
- The most common barrier for cancer rehabilitation is funding. Some services highlighted the lack of growth in the cancer rehabilitation workforce. This has a significant impact on capacity and leads to gaps in service provision and unmet need.
- There are significant gaps in community provision for cancer rehabilitation services. South East London STP has a specialist head and neck cancer community team, with no provision for other pathways. The only community services found in the other five STP areas were those provided by hospices or third sector organisations. Gaps in community provision puts increased pressure on acute cancer rehabilitation services and so whilst acute services are relatively well spread, they are potentially struggling to meet demand. Furthermore, with a dependency on acute provision it is likely that few patients are being offered care close to home.
- Physical activity programmes for cancer patients are provided across all London STPs, but provision is variable. South East London has the highest number of services (n=9) with only two programmes in North West London. Programmes which are not cancer specific are also variable across the STPs.
- The main barrier for physical activity programmes was reported as funding (which traditionally comes from a range of sources including via CCGs, local authorities and the third sector). This was particularly so in the context of workforce provision. Service providers also noted a lack of awareness of their services, impacting referrals.

Recommendations

Phase one – (2019/2020)

1.1. TCST and London based Cancer Alliances to triangulate data from this report with upcoming workforce data available through Alliance led mapping (due Autumn 2019), and make recommendations regarding rehabilitation provision/commissioning improvements to the London Cancer Commissioning Board.

1.2. All CCGs and STPs to build on the momentum of ongoing system reconfiguration (in the context of developing Integrated Care Systems and Primary Care Networks), and work collaboratively to

- examine the commissioning, provision of and access to, cancer rehabilitation locally; and
- develop an action plan for improvement in personalised care provision

1.3. STPs, Cancer Alliances and Macmillan to work in partnership with local cancer rehabilitation services and voluntary services to implement the TCST service improvement tools (available [here](#)), to support service development and improvement, as well as to collect quality baseline data, in line with the TCST data recommendation report (available [here](#))

Phase two – (2020 - 2023)

2.1. Building on recommendations 1.2 and 1.3, CCGs and STPs to work collaboratively with key partners (including non-cancer services, the voluntary sector, primary care networks and Integrated Care Systems) to implement improvements to ensure provision of comprehensive cancer rehabilitation at the appropriate level for **all cancer patients, across all tumour groups and at every stage of the pathway**, including prehabilitation and palliative rehabilitation.

2.2. Providers to commit to developing rehabilitation services in line with increasing numbers of people diagnosed with cancer, relevant developments in personalised care provision, as well as advancements in medical treatment, adapting to provide timely and high-quality services in line with changing demands.

Purpose

The purpose of this document is to:

- Demonstrate the results of comprehensive mapping undertaken of adult cancer rehabilitation services in London and West Essex and;
- Give an overview of service availability in London and West Essex, broken down by STP
- Provide recommendations for commissioners to develop and enhance cancer rehabilitation services in London
- Provide recommendations for TCST and the Cancer Alliances in developing intelligence further, and aligning with other work in the region

Background

The Transforming Cancer Services Team (TCST) undertook a scoping exercise between April and December 2016 to better understand the scope and availability of cancer rehabilitation services across London and West Essex. This scoping exercise was designed to inform the development of commissioning guidance for cancer rehabilitation services in the region¹. The report was published in February 2017 and is available [here](#). TCST engaged with key stakeholders and partners in conducting this scoping work, which was fully funded by Macmillan Cancer Support.

The key findings of the scoping report demonstrated:

- A lack of good data on cancer rehabilitation services
- Poor awareness and understanding of the breadth and scope of cancer rehabilitation
- Significant gaps in cancer rehabilitation services and the rehabilitation workforce across London and West Essex.
- A lack of evidence of the impact of rehabilitation services on patient care

Following this scoping exercise, TCST undertook three main pieces of work to inform the upcoming TCST *Commissioning Guidance for Cancer Rehabilitation* due for publication in Summer 2019:

- [Cancer Rehabilitation Data Recommendation Report](#) (published October 2017)
- [Development of Cancer Rehabilitation Service Improvement Tools](#) (published December 2018)
- Mapping of Pan-London Cancer Rehabilitation Services (this report)

This report outlines what cancer rehabilitation services are available across the region. The methodology and narrative analysis are provided below, and an interactive map showing

¹ Cancer rehabilitation: a scoping report for London, Transforming Cancer Services Team, 2017

services has also been developed, through which services can be shown by STP and/or by type of service. This is available [here](#).

Findings from this report should be read in conjunction with relevant reports on rehabilitation. For example, the NHS England *Improving Rehabilitation Services Programme Regional Report for London*² and the *Macmillan Cancer Support 'Allied Health Professionals Workforce (2018)* report provide key insights into the importance of AHPs in rehabilitation. AHPs support people affected by cancer to improve quality of life, address unmet needs and consequences of cancer and its treatment, for example fatigue, pain, mobility and nutrition. In addition, AHPs facilitate self-management and deliver holistic interventions which support emotional, physical, practical and financial needs of people living with and beyond cancer³.

This report will accompany the London and West Essex AHP workforce mapping reports due to be published by the London Cancer Alliances (due Autumn 2019) and the revised mapping of lymphoedema services which is currently being undertaken by the Lymphoedema Community of Practice supported by TCST (due Autumn 2019). The intelligence from these combined documents will, for the first time, provide a comprehensive overview of the current position of cancer rehabilitation services and workforce in London and will make recommendations for improvement to ensure that high quality provision is available for all individuals with cancer in London.

Importance of cancer rehabilitation in the region

The role of AHPs in providing cancer rehabilitation

The recently launched *NHS Long Term Plan* places significant focus on personalised care across the whole health system⁴. Rehabilitation is integral for providing personalised care, particularly for those living with and beyond cancer. However, the *National Cancer Patient Experience Survey* provides evidence of poor scores across all London STPs for cancer patients feeling supported by health and social care staff, and low numbers of patients reporting that they received a care plan or information about the effects of cancer treatment⁵. This suggests there is a need for additional investment and provision of cancer rehabilitation services to meet the needs of the London population.

The role of AHPs in providing cancer rehabilitation is well documented and there is much literature outlining best practice. The *NHS England Commissioning Guidance for Rehabilitation*⁶ provides a blueprint for planning and delivering services and a high-level overview of the importance of rehabilitation. The guidance sets out helpful principles and expectations for rehabilitation, as well as practical support for commissioners.

The *NHS England Improving Rehabilitation Services Programme Regional Report – London*⁷, outlines some of the specific challenges for rehabilitation in London. The report highlights the complexity of the London region due to its size and scale. Whilst the region

² NHS England Improving Rehabilitation Services Programme Regional Report – London, NHS England, 2015

³ Allied Health Professional Workforce Report, Macmillan, 2018

⁴ NHS Long Term Plan, NHS England, 2019

⁵ National Cancer Experience Survey, 2017, TCST Dashboard:

<https://public.tableau.com/profile/transforming.cancer.services.for.london#!/vizhome/NationalCancerPatientExperienceSurvey2017London/Story1?publish=yes>

⁶ Commissioning Guidance for Rehabilitation, NHS England, 2016

⁷ NHS England Improving Rehabilitation Services Programme Regional Report – London, NHS England, 2015

is compact, it serves the 9.2 million population and incorporates five STPs, 32 statutory-based CCGs, 33 Local Authorities, 39 Acute hospitals, nine mental health trusts, three Academic Health Science Networks, three Cancer Alliances and the pan-London Transforming Cancer Services Team.

Furthermore, the *National Cancer Action Team (NCAT) rehabilitation pathways*, as hosted by Macmillan⁸, provide a comprehensive summary of the interventions provided by AHPs for people living with and beyond cancer, as part of cancer rehabilitation.

Additionally, NHS England published its report; the *Quick Guide: the role of allied health professionals in supporting people to live well with and beyond cancer* in October 2018, providing an outline of the role of AHPs in delivering care to cancer patients. This report recognises the importance of supporting and valuing AHPs in delivering the highest standards of care to those living with and beyond cancer⁹.

The population need for cancer rehabilitation

In the 2013 report *Throwing light on the consequences of cancer and its treatment*, Macmillan Cancer Support estimated that 25% of people living after cancer treatment in the UK face long-term effects of treatment¹⁰. This can include a wide range of physical, psychological and social consequences of treatment, and some of these might not arise for many months or years after treatment has taken place. This report also highlighted that many people receiving cancer treatment will have short-term consequences of treatment, which require rehabilitation services. As outlined above, rehabilitation is integral to addressing these needs.

“There is limited understanding of the challenge of working with this patient group and amount of time that is required to provide appropriate support.”

Cancer rehabilitation service

Figure 1 outlines the number of people who have been diagnosed with cancer in the last 21 years, and are living with or after cancer, per STP in the London and West Essex regions. This data gives an indication of the likely number of people living with the long-term effects per STP, highlighting the need for well-resourced and integrated cancer rehabilitation services.

“It is difficult to demonstrate short term outcomes to sustain a service when the real impact is demonstrated at a later point”

Cancer rehabilitation service

Research conducted by Macmillan Cancer Support estimates that the number of people living with or after a cancer diagnosis will increase at a rate of 3% per year, suggesting the need for cancer rehabilitation services is likely to grow. It is also predicted that the age profile of those living with or after a cancer

diagnosis will change, with 73% of those living with or after a cancer diagnosis nationally

⁸ Cancer Rehabilitation Pathways, Macmillan and National Cancer Action Team, 2013. Available here:

<https://www.macmillan.org.uk/assets/macmillan-cancer-rehabilitation-pathways.pdf>

⁹ Quick Guide: the role of allied health professionals in supporting people to live well with and beyond cancer, NHS England, 2018

¹⁰ Throwing light on the on the consequences of cancer and its treatment, Macmillan, 2013

to be aged over 65 by 2030, suggesting additional complexity to individual's needs due to the increased likelihood of multi-morbidities. If these increased needs are not met, there are likely to be significant impacts and quality of life, as well as cost implications for the NHS and the wider economy, with an increased longer-term demand on services and potential impacts on the ability to work or study¹¹.

Figure 1. 2017 Cancer prevalence figures per STP in the last 21 years¹²

| STP | Number of people living with or after cancer diagnosis in last 21 years | Predicted number of people living with long-term consequences of treatment |
|----------------------|---|--|
| North Central London | 39,094 | 9774 |
| North East London | 43,204 | 10,801 |
| North West London | 54,268 | 13,567 |
| South West London | 45,901 | 11,475 |
| South East London | 49,273 | 12,318 |

Methodology

A Task & Finish group was formed in January 2018 to oversee this mapping project. The group met regularly to design and implement the project methodology. An external project manager was employed for seven weeks to support the project.

Definition

For the purposes of this project, the Task & Finish Group defined cancer rehabilitation services as those providing the services outlined below, with the objective of treating the consequences of cancer and cancer treatment:

- Physiotherapy
- Occupational therapy
- Speech and language therapy
- Nutrition & Dietetics
- Physical activity programmes

¹¹ Statistics fact sheet, Macmillan, 2017 available here: https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf

¹² The Cancer Prevalence in England: 21 year prevalence by demographic and geographic measures' workbook, produced by a collaboration of TCST, NHS National Cancer Registry and Analysis Service (NCRAS), Public Health England and Macmillan Cancer support. Available here: <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

Lymphoedema services and questions specific to workforce were excluded, as other documents addressing these are due for publication in Autumn 2019. The intelligence in this report should be triangulated with these reports once available. To allow sufficient scope whilst ensuring that cancer rehabilitation remained the primary focus, only services with a direct referral route for cancer patients were included in this report.

Surveys

To obtain data on cancer rehabilitation services across the region, the Task & Finish Group developed two surveys:

- Survey for service providers
- Survey for commissioners

The surveys were developed in collaboration with key stakeholders, including members of the three Cancer Alliances in London, and were subsequently tested with services and commissioners before implementation. The survey templates can be found in Appendix B.

The surveys aimed to capture the following information on cancer rehabilitation services:

- Overview of service provision
- Location
- Access
- How the service is commissioned
- Evaluation and Quality Assurance of the service

Survey for service providers

To disseminate the survey for service providers, TCST adopted a snowball approach. This involved:

- The T&F group and key stakeholders in the three London Cancer Alliances (UCLH Collaborative, RM Partners and South East London Cancer Alliance) helped to identify a lead within London's 22 acute trusts which deliver cancer services
- The survey was then circulated to these leads via the online platform Survey Monkey, for completion online
- The survey asked each lead to identify and provide the contact details for the rehabilitation services which they routinely referred their patients in to
- Once they had completed the survey, the leads forwarded the online survey to other relevant services, including other rehabilitation services, to provide additional detail
- These additional services were then also followed up by the external project manager via email and/or telephone call to quality assure the content of the survey answers

The T&F group also used this snowball approach to identify community based rehabilitation services which acute trusts routinely referred their patients in to. Further community based cancer rehabilitation services were also identified through the TCST Rehabilitation Steering Committee and Macmillan Information and Support Centres.

Survey for commissioners

The T&F group contacted each of London's 32 Clinical Commissioning Group (CCG)s' cancer clinical or cancer commissioning leads, as well as the lead in West Essex CCG. Each lead was initially contacted via email, and followed up with a telephone call to request a time to conduct the commissioner survey via telephone.

The T&F group also contacted key leads at the NEL Commissioning Support Unit (NELCSU), with each lead having responsibility for providing cancer commissioning support to CCGs. This contact determined if there were specific cancer rehabilitation services commissioned by NELCSU on behalf of the London CCGs they support.

Mapping cancer specific exercise programmes

The T&F group also mapped cancer specific exercise programmes available across London and West Essex. To obtain this data, the group contacted each of London's 33 Local Authority Public Health leads to ascertain whether there were any cancer specific exercise programmes available in their locality. The T&F group also engaged with Macmillan Information and Support Centres to identify cancer specific exercise programmes which they signpost their patients towards. Leisure centre providers including Better, Fusion Lifestyles, Everyone Active and Enable Leisure, were also contacted and asked to provide information about specific cancer exercise programmes they ran or were aware of.

Desk research and quality assurance

To complement the mapping exercises described above, and where there were significant gaps in intelligence obtained, other services were located through desk research. Data received from the surveys were triangulated with information contained in online service directories, for example the *London Cancer* Directory of Services, the Dimpleby Cancer Care Map, and online service directories provided by local authorities. These data were then shared with some members of the TCST Rehabilitation Steering Group, who were asked to validate the information in their locality to ensure accuracy.

As the data collection took place over a period of several months, information was quality assured with members of the TCST Rehabilitation Steering Group, to ensure that it was up to date.

Project findings - summary of responses

Service provider response rate

Information was received from 19 of the 22 acute trusts approached to complete the survey.

No information was provided from three trusts; the Princess Alexandra Hospital NHS Trust, Moorfields Eye Hospital NHS Foundation Trust and the Royal National Orthopaedic Hospital NHS Trust. The primary reason for this was the difficulty in identifying a contact lead who could provide the relevant information and/or complete the survey on behalf of these trusts.

Levels of survey completion varied and all information provided in completed surveys can be seen via the interactive map of cancer rehabilitation services in London, available [here](#).

Commissioner response rate

Challenges were experienced in obtaining responses from commissioners. Where contact was made with identified leads, many of them were not sure who the right person to speak to was, and/or were not able to supply information about specific cancer rehabilitation services.

The T&F group therefore engaged with the North West London Collaboration of Clinical Commissioning Groups Cancer Performance Manager who took the survey request to key commissioning partners across London. Upon discussion it became clear that it is currently not possible to extract specific information around cancer rehabilitation from commissioning contracts. This is due to the complexities in the way contracts are currently commissioned; they do not contain service specifications or data flows which can be identified as cancer rehabilitation. Instead, some activity is paid for as part of block contracts, not as individual packages of care which are specific to cancer. For example, where a cancer patient requires physiotherapy, they are referred to the relevant service but this is not recoded as an 'oncology physiotherapy' intervention.

This presents a significant limitation in this report with regards to obtaining data on how cancer rehabilitation services are commissioned. It does however, demonstrate that some cancer rehabilitation services are commissioned via block contracts. Whilst this might provide benefits for commissioning, and potentially be beneficial in commissioning integrated care, it is much more challenging to analyse accurately the level of service provision for cancer rehabilitation and whether this is sufficiently meeting local needs.

As this report has already demonstrated, there is a high level of demand, which is only going to increase. Therefore, the recording and extraction of cancer specific information is part of a key recommendation of this report; for commissioning partners to work with TCST and the London Cancer Alliances to examine how services are commissioned as well as what provision is commissioned in line with local needs.

Key findings: cancer rehabilitation services in London and West Essex

Interactive map of rehabilitation services

All services mapped as part of this project and outlined below, can be viewed on an interactive map. This resource allows rehabilitation services to be seen per STP, CCG and by type of service. The interactive map also provides greater detail about each service, for example how the service is accessed and waiting times, where this intelligence was obtained. This resource is available [here](#) and instructions of how to use it are provided within.

Map of rehabilitation and physical activity services

All rehabilitation and physical activity services mapped as part of this project are illustrated on the maps provided in Figures 2 and 3. Each service name is provided in the key and the type of service (acute, community, hospice, local authority or limited company) is represented by the icon also outlined in the key. The map highlights the distribution of cancer rehabilitation and physical activity services across London and West Essex. Analysis of the services in each STP is provided in the following section. All maps provided in this report can be [downloaded here](#).

Figure 2: Map of all cancer rehabilitation services in London and West Essex

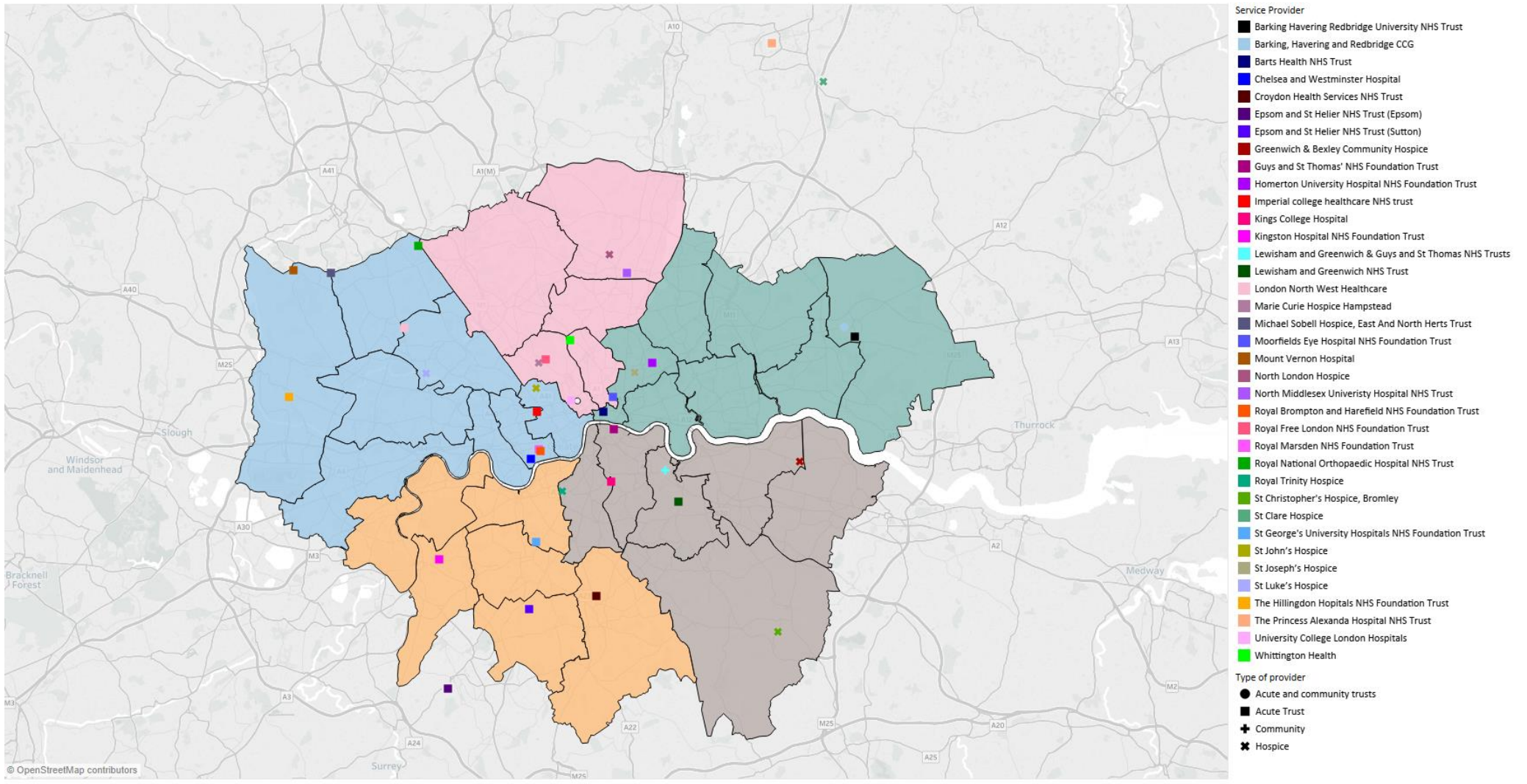
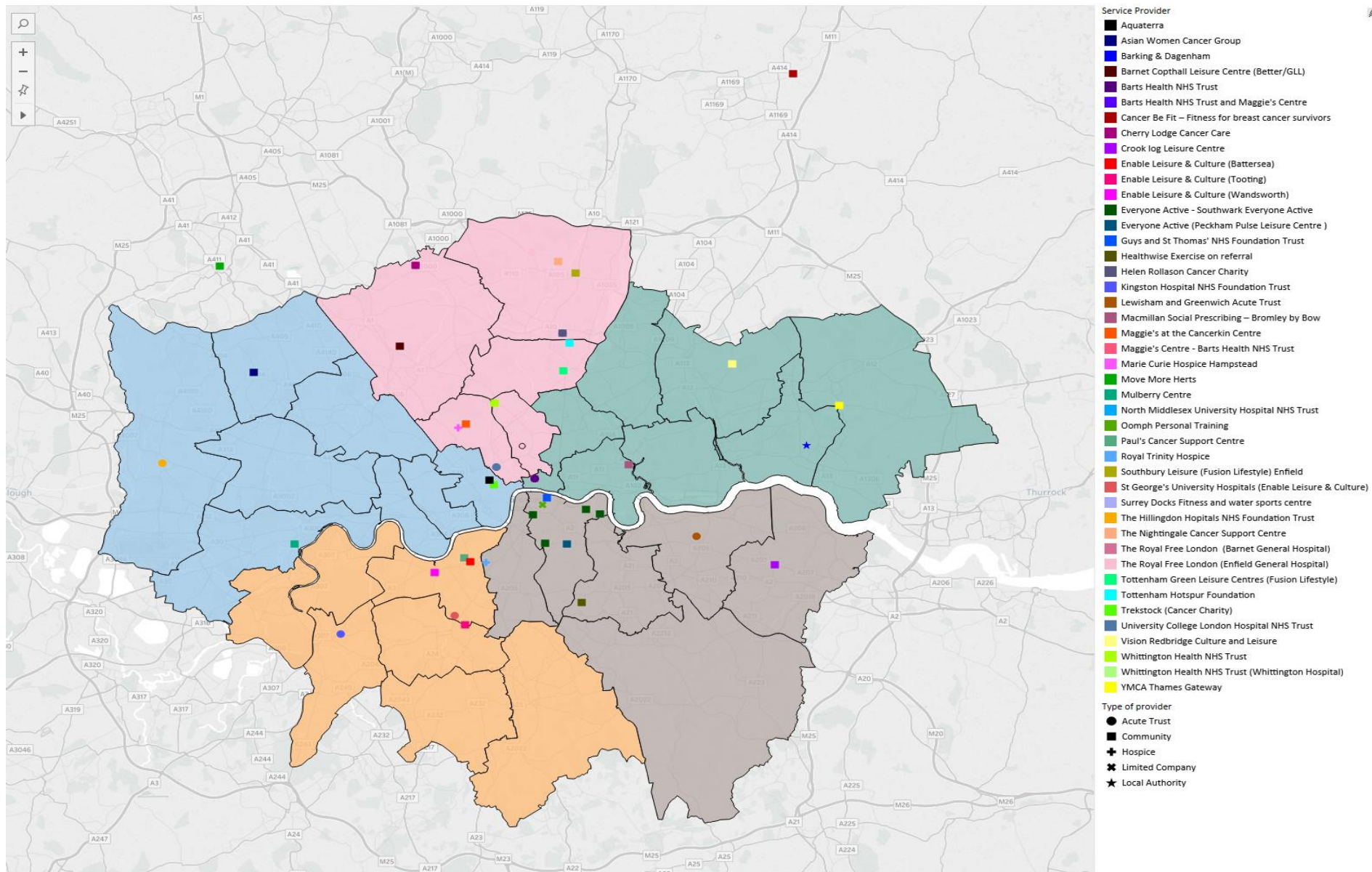


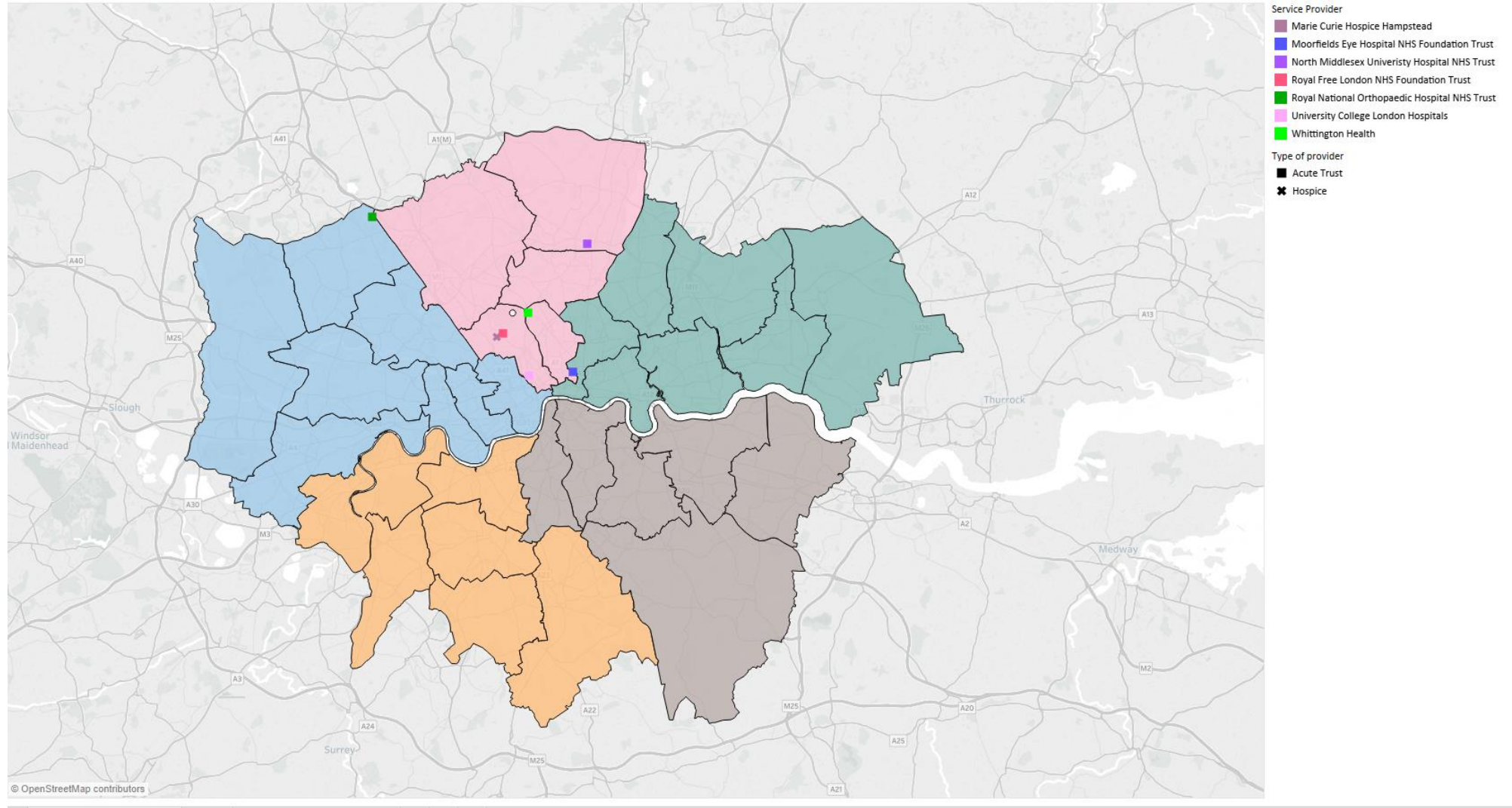
Figure 3: Map of all physical activity services in London and West Essex



NORTH CENTRAL LONDON

Cancer rehabilitation services

Figure 4: Map of cancer rehabilitation services in North Central London



Acute services

There was a range of provision of acute cancer rehabilitation services reported across North Central London (NCL). Physiotherapy, dietetics, and occupational therapy are offered for cancer patients at four of the acute trusts (**University College London Hospital NHS Trust, Royal Free London NHS Foundation Trust, North Middlesex University Hospital NHS Foundation Trust and Whittington Health NHS Trust**). Speech and language therapy is provided at all of these trusts with the exception of Whittington Health NHS Trust.

University College London Hospital NHS Trust provides specialised inpatient and outpatient physiotherapy and occupational therapy as part of their acute oncology, inpatient haematology services and the surgical therapy team. Physiotherapy services also provide specific exercise activity with physiotherapists for cancer patients. Inpatient and outpatient specialist speech and language therapy is provided as part of the head and neck cancer pathway.

The oncology services at the **Royal Free London NHS Foundation Trust** reported the provision of inpatient and outpatient dietetics services, inpatient occupational therapy and physiotherapy, with outpatient physiotherapy services available for breast cancer patients. These services are provided on the Hampstead Site and no specialist cancer rehabilitation services are provided at Chase Farm Hospital. The Royal Free London NHS Foundation Trust also refers patients onwards to exercise programmes that they can access in their local area (as available).

North Middlesex University Hospital NHS Foundation Trust provides physiotherapy, dietetics, occupational therapy and speech and language therapy for cancer patients.

Whittington Health NHS Trust's Cancer Services Team based at the Whittington Hospital provides inpatient and outpatient physiotherapy, dietetics and occupational therapy.

No response was received from the Sarcoma Unit of the London Sarcoma Service located at the **Royal National Orthopaedic Hospital Trust** during this mapping exercise. However, desk research indicates that there is provision of a specialised service of physiotherapy and occupational therapy for sarcoma patients, including an amputee service.

No response was received from **Moorfields Eye Hospital NHS Foundation Trust**.

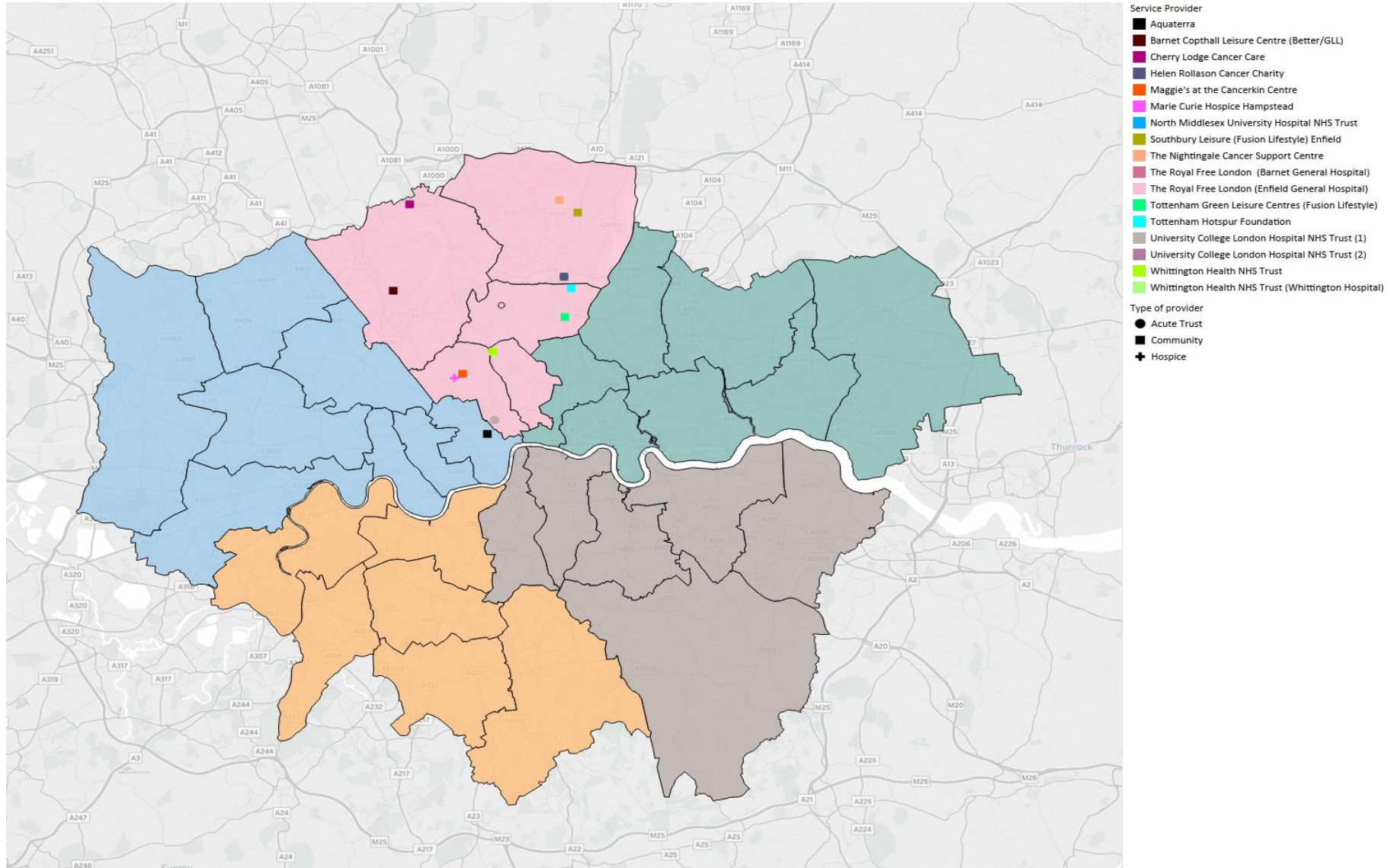
Community and third sector

In the community, the **Aquaterra** Exercise on Referral and Adult Weight Management service provides a range of treatments including occupational therapy, physiotherapy, speech and language therapy, and dietetics based on patient need.

Marie Curie Hospice in Hampstead offers physiotherapy, occupational therapy, dietetics services as well as Music Therapy, Complementary Therapies and Hydrotherapy to in and out patients.

Physical activity services

Figure 5: Map of physical activity services in North Central London



A range of physical activity programmes were reported across NCL.

Move4you is a 12-week structured exercise programme provided specifically for cancer patients and delivered by the Tottenham Hotspurs Foundation. It is funded by the Big Lottery. The programme begins with an initial assessment, then a follow up on completion of the 12 weeks exercise programme, and again at six and 12 months. Sessions are delivered at Southbury Leisure Centre, Tottenham Green Leisure Centre, Cophall Leisure Centre, Whittington Hospital and Barnet Hospital. Referrals are received from:

- University College London Hospital NHS Trust
- Royal Free London NHS Foundation Trust
- Whittington Health NHS Trust
- North Middlesex University Hospital NHS Foundation Trust
- Cherry Lodge Cancer Care
- The Nightingale Cancer Support Centre

North Middlesex University Hospital NHS Trust also works with the Move4you programme delivered by Tottenham Hotspurs Foundation to provide chair based exercise for radiotherapy patients on a weekly basis. These classes are tailored to individual patients and their relatives.

The Helen Rollason Cancer Charity provides weekly pilates classes for cancer patients, and **Maggie's at the Cancerkin** centre provides an exercise programme for cancer patients called Can Exercise, comprising yoga t'ai chi and pilates classes.

The Whittington Health NHS Foundation Trust works in partnership with the **Move Dance Feel** exercise programme provided by Emily Jenkins, and is free to access for cancer patients.

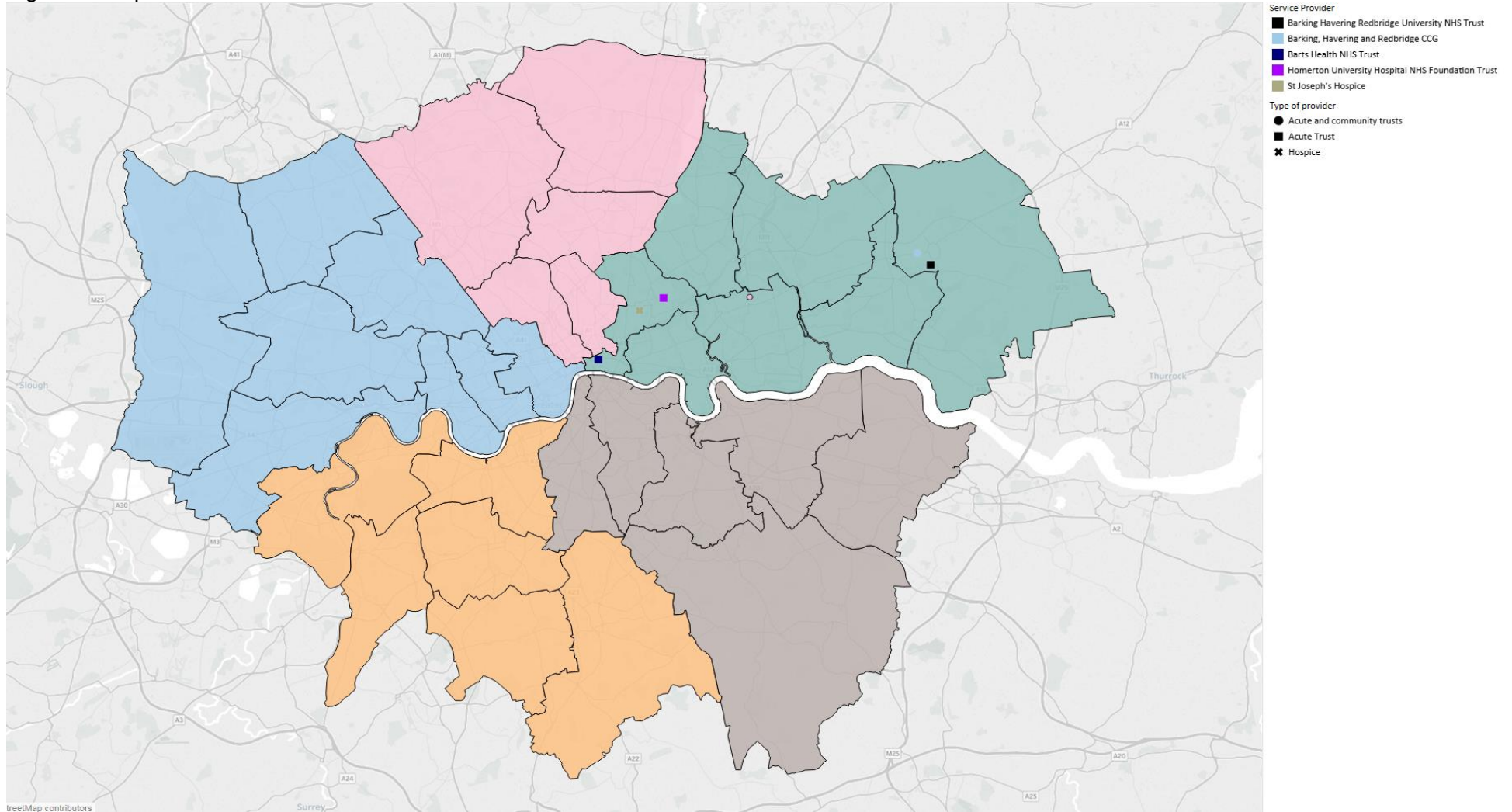
Marie Cure Hospice at Hampstead provides a gym based exercise programme which cancer patients can access as in or outpatients

Trekstock provides the **Renew Exercise programme** for young adults, based at the Central YMCA, but open to referrals from across all London STPs. This is a 12-week exercise programme working with a Level 4 Cancer Rehabilitation qualified instructor to develop a tailored exercise plan, and is delivered by 1 to 1 gym-based sessions.

NORTH EAST LONDON

Cancer rehabilitation services

Figure 6: Map of cancer rehabilitation services in North East London



Acute services

There was a range of variable provision of acute cancer rehabilitation services reported across North East London (NEL).

Barts Health NHS Trust provides an Oncology Therapies department located at **St Bartholomew's Hospital**, which delivers inpatient physiotherapy, speech and language therapy, occupational therapy and dietetics, as well as art and music therapy. The service also provides outpatient physiotherapy.

The specialist neuro-oncology rehabilitation service at **St Bartholomew's Hospital**, provides inpatient, specialist and intensive physiotherapy and occupational therapy for cancer patients with complex neurological problems due to their cancer or cancer treatment.

This team also provides outpatient physiotherapy services at **Whipps Cross Hospital** for one day a week, available to all Barts Health oncology patients, as well as local residents.

Those receiving care at the other **Barts Health NHS Trust** sites have access to inpatient general (non-cancer specific) rehabilitation services and once discharged, they can access a musculoskeletal outpatient service. There is also a prehabilitation service provided through an outpatient clinic.

Barking Havering Redbridge University NHS Trust provides rehabilitation services as part of the Integrated Therapies Department – Medical Specialities and Oncology Pathway and the cancer services. Services include physiotherapy, speech and language therapy, occupational therapy, dietetics and a prehabilitation course.

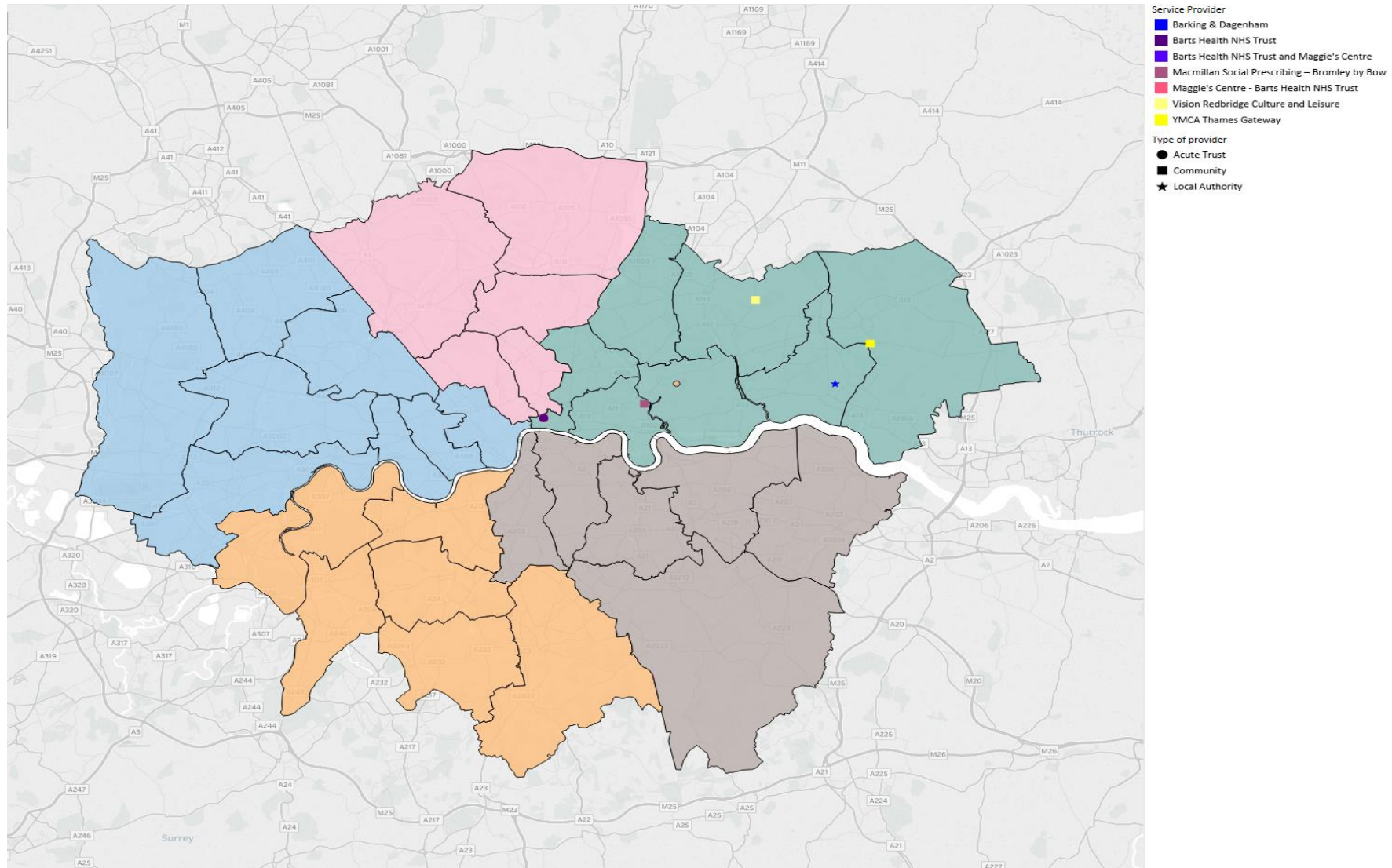
Homerton University Hospital NHS Foundation Trust works in partnership with other local cancer centres (including Barts Health NHS Trust, Royal Free London NHS Foundation Trust and University College London Hospital NHS Trust) to provide tumour specific services. The trust itself provides a dietetics team for colorectal and upper gastro-intestinal cancer patients.

Community and third sector

St Joseph's Hospice offers inpatient, outpatient and domiciliary physiotherapy and occupational therapy services.

Physical activity services

Figure 7: Map of physical activity services in North East London



A range of physical activity programmes were reported across NEL.

The London Borough of Barking and Dagenham provides a 12-week exercise programme on referral for those with a medical condition which could be improved by increasing physical activity levels, which includes cancer.

Vision Redbridge Culture and Leisure and **YMCA Thames Gateway** provide a 12-week cancer rehabilitation exercise programme.

The Bromley By Bow Centre, Macmillan Social Prescribing team also work in partnership to provide the Move Dance Feel dance classes which are free to access for cancer patients. The centre also provides yoga classes for people living with and beyond cancer, delivered by Supply Yoga.

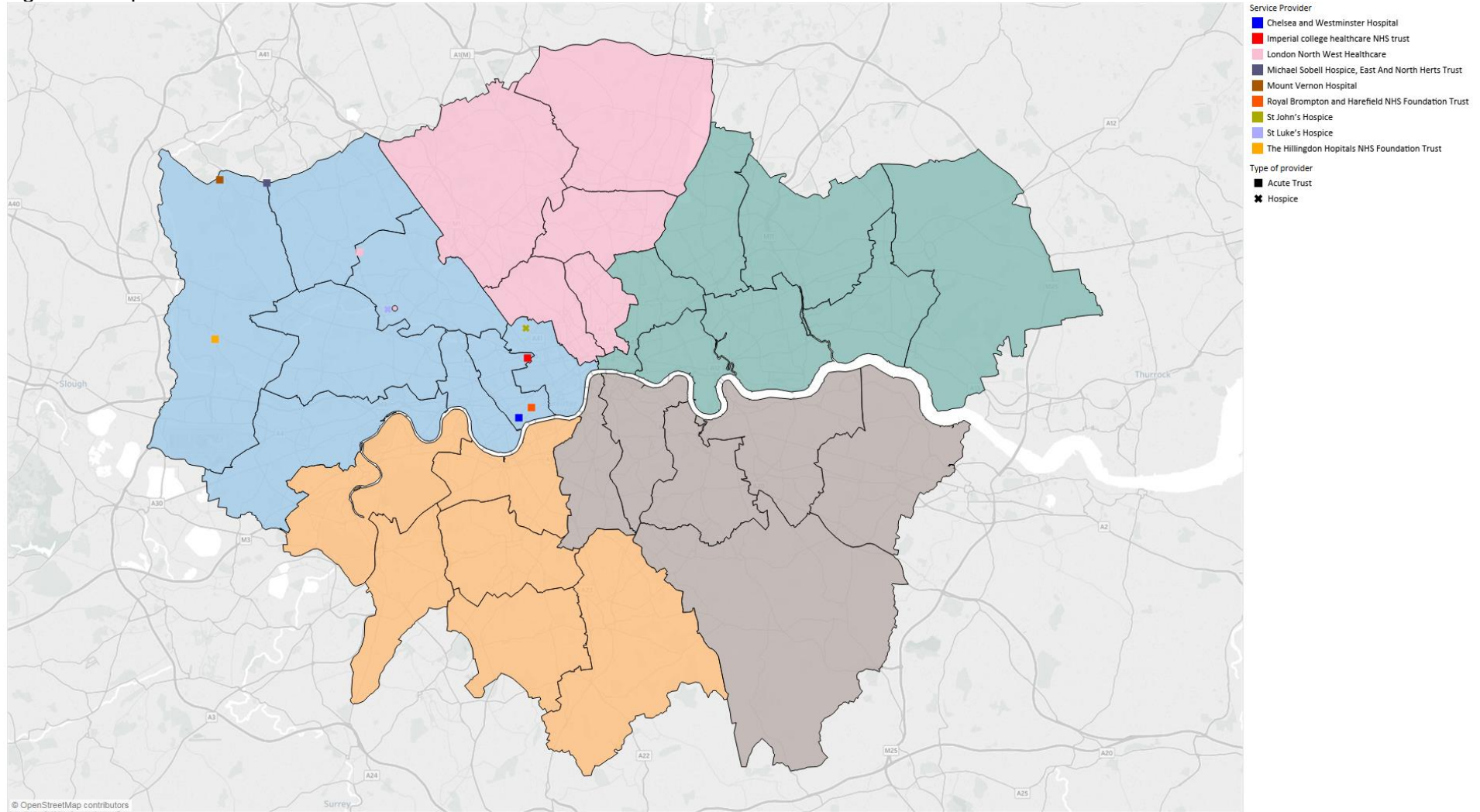
Barts Health NHS Trust provides exercise classes delivered by the physiotherapy service, and in partnership with the **Maggie's Centre**, provides the 'Where now?' (formerly the Cancer Transitions) programme, which delivers a 7-week course comprising of 45 minutes of exercise followed by talks by physiotherapists/dieticians/oncologist/psychologists. The Maggie's Centre at Barts Health NHS Trust also provides t'ai chi and yoga classes for cancer patients.

Trekstock provides the **Renew Exercise programme** for young adults, based at the Central YMCA, but open to referrals from across all London STPs. This is a 12-week exercise programme working with a Level 4 Cancer Rehabilitation qualified instructor to develop a tailored exercise plan, and is delivered by 1 to 1 gym-based sessions.

NORTH WEST LONDON

Cancer rehabilitation services

Figure 8: Map of cancer rehabilitation services in North West London



Acute services

There was a range of provision of acute cancer rehabilitation services reported across North West London (NWL). Physiotherapy, occupational therapy, speech and language and therapy and dietetics are provided specifically for cancer patients at three of the main acute trusts; the **Royal Brompton and Harefield NHS Foundation Trust**, **Imperial College Healthcare NHS Trust** and **Chelsea and Westminster Hospital NHS Foundation Trust**.

Imperial College Healthcare NHS Trust also provides art and music therapy and hydrotherapy, as well as early acute rehabilitation is also provided for neuro-oncology, haem-oncology, thoracic surgery, upper GI surgery, acute oncology and MSCC pathway patients. This trust also provides a comprehensive prehabilitation programme called 'PREPARE'. This programme works with patients ahead of surgery and comprises of physical activity, respiratory exercises and support with eating well, as well as psychosocial support.

The Royal Brompton and Harefield NHS Foundation Trust also delivers a physiotherapy service for pulmonary rehabilitation which accepts post-surgical lung cancer patients, as well as those with COPD. This service focuses on strategies to manage breathlessness.

The Hillingdon Hospitals NHS Foundation Trust provides inpatient oncology physiotherapy and occupational therapy at **Mount Vernon Hospital**. Patients of other sites are referred by their Clinical Nurse Specialist to general rehabilitation services, including inpatient and outpatient physiotherapy/

London North West University Healthcare NHS Trust provides dietetic services and speech and language therapy for patients with head and neck cancer. The Trust also provides an upper and lower gastrointestinal cancer treatment consequences service, but this is not delivered by specific AHP staff. Occupational therapy is provided for end of life patients, and **St Mark's Hospital** provides a biofeedback team for those with functional bowel disorders, many whom have had cancer. The team includes a physiotherapist.

Community and third sector

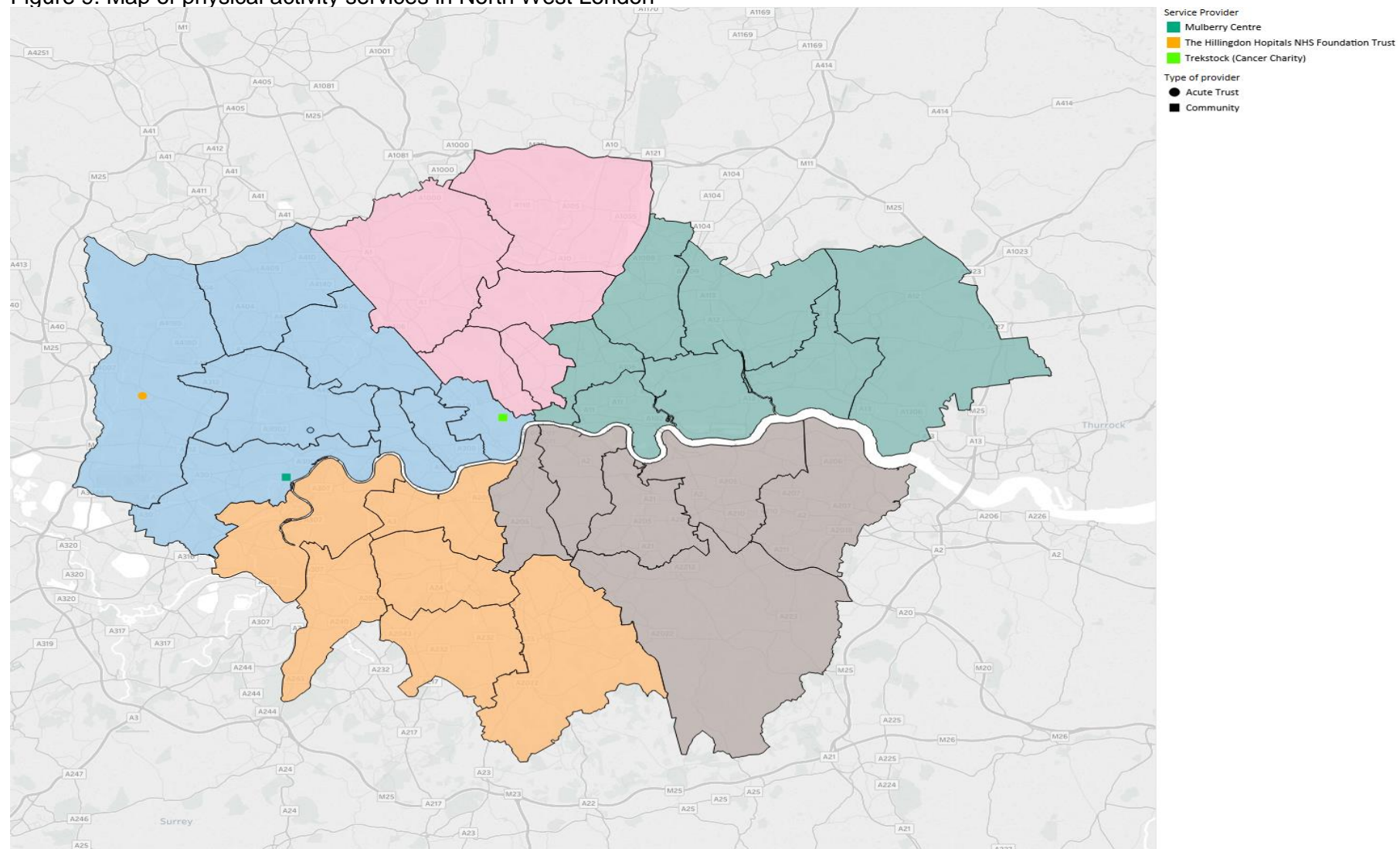
The Michael Sobell House Hospice is located at Mount Vernon as a 20-bed hospice and offers physiotherapy, occupational therapy, speech and language therapy and dietic services.

St John's Hospice provides palliative occupational therapy and physiotherapy services.

St Luke's Hospice offers physiotherapy, as does the **North London Hospice** which also provides exercise as part of its physiotherapy services and the Health and Wellbeing Centre.

Physical activity services

Figure 9: Map of physical activity services in North West London



Three physical activity programmes were reported across NWL.

The Hillingdon Hospitals NHS Foundation Trust provides a cancer rehabilitation exercise class as part of the 'Let's Get Moving Campaign'. The is delivered in partnership with Fusion Leisure Centre and is funded in part by the trust, and part by patient donation per class.

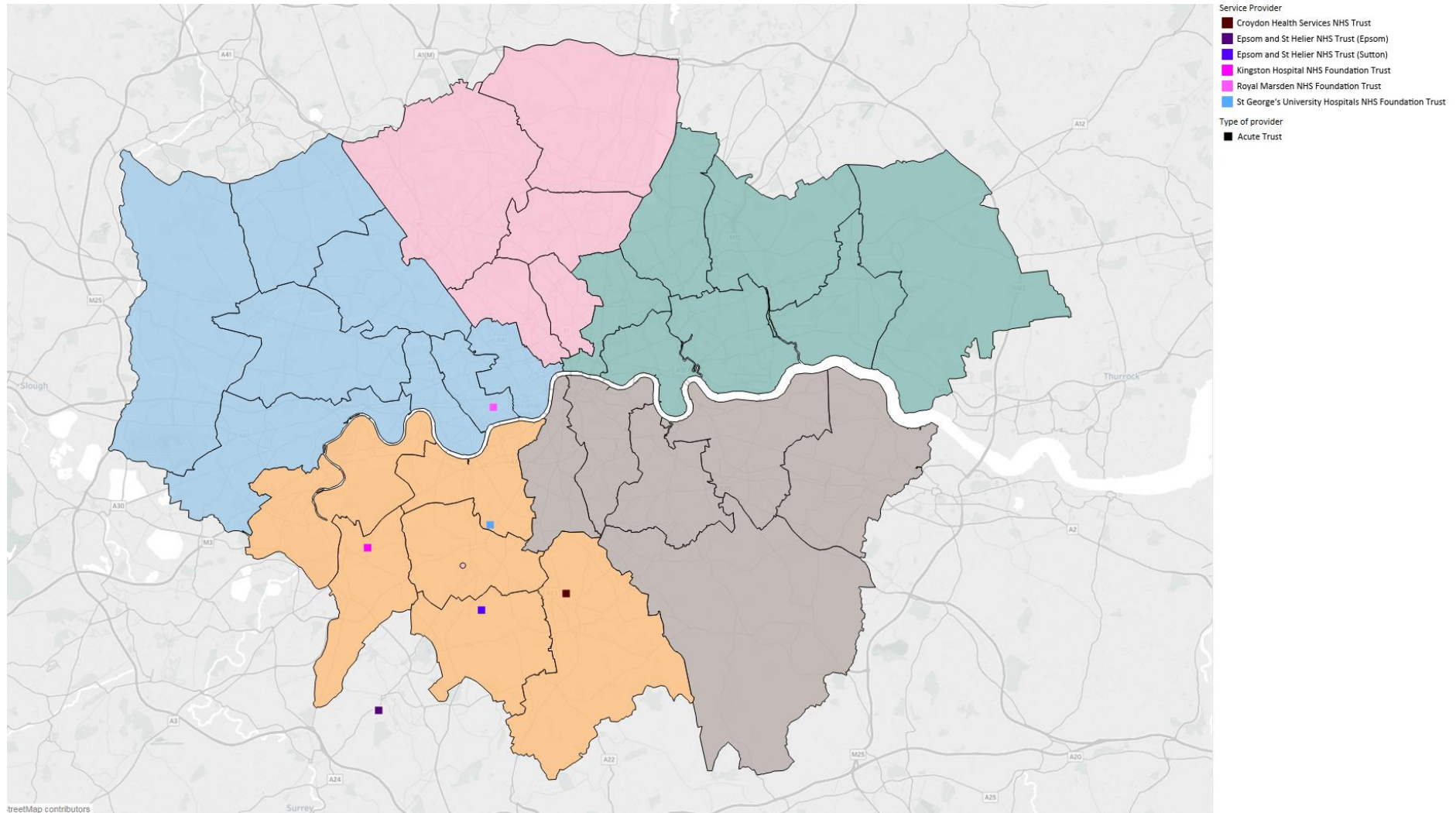
The Mulberry Centre provides various exercise classes for cancer patients, including pilates, t'ai chi and yoga classes.

Trekstock provides the **Renew Exercise programme** for young adults, based at the Central YMCA, but open to referrals from across all London STPs. This is a 12-week exercise programme working with a Level 4 Cancer Rehabilitation qualified instructor to develop a tailored exercise plan, and is delivered by 1 to 1 gym-based sessions.

SOUTH WEST LONDON

Cancer rehabilitation services

Figure 10: Map of cancer rehabilitation services in South West London



Acute services

There was a range of provision of acute cancer rehabilitation services reported across South West London (SWL). Physiotherapy, dietetics, and speech and language therapy are offered for cancer patients at three of the acute trusts in SWL (**Royal Marsden NHS Foundation Trust, Kingston Hospital NHS Foundation Trust and St George's University Hospitals NHS Foundation Trust**). Occupational therapy is provided at all of these trusts with the exception of **St George's University Hospitals NHS Foundation Trust**.

In addition to rehabilitation services for both inpatients and outpatients, **The Royal Marsden NHS Foundation Trust** also delivers a limited prehabilitation service, as well as art and music therapy and exercise programmes for cancer patients. The Royal Marsden is a tertiary referral centre and does not have a defined catchment area.

Kingston Hospital NHS Foundation Trust provides an incontinence service, as well as comprehensive rehabilitation services for inpatients and outpatients.

In addition to the physiotherapy, speech and language therapy and dietetics provided, **St George's University Hospitals NHS Foundation Trust** also offers an incontinence and erectile dysfunction services as part of the urology department.

Croydon Health Services NHS Trust provides cancer rehabilitation through the adult therapy services. This comprises of speech and language therapy and dietetics, as well as domiciliary physiotherapy, community occupational therapy.

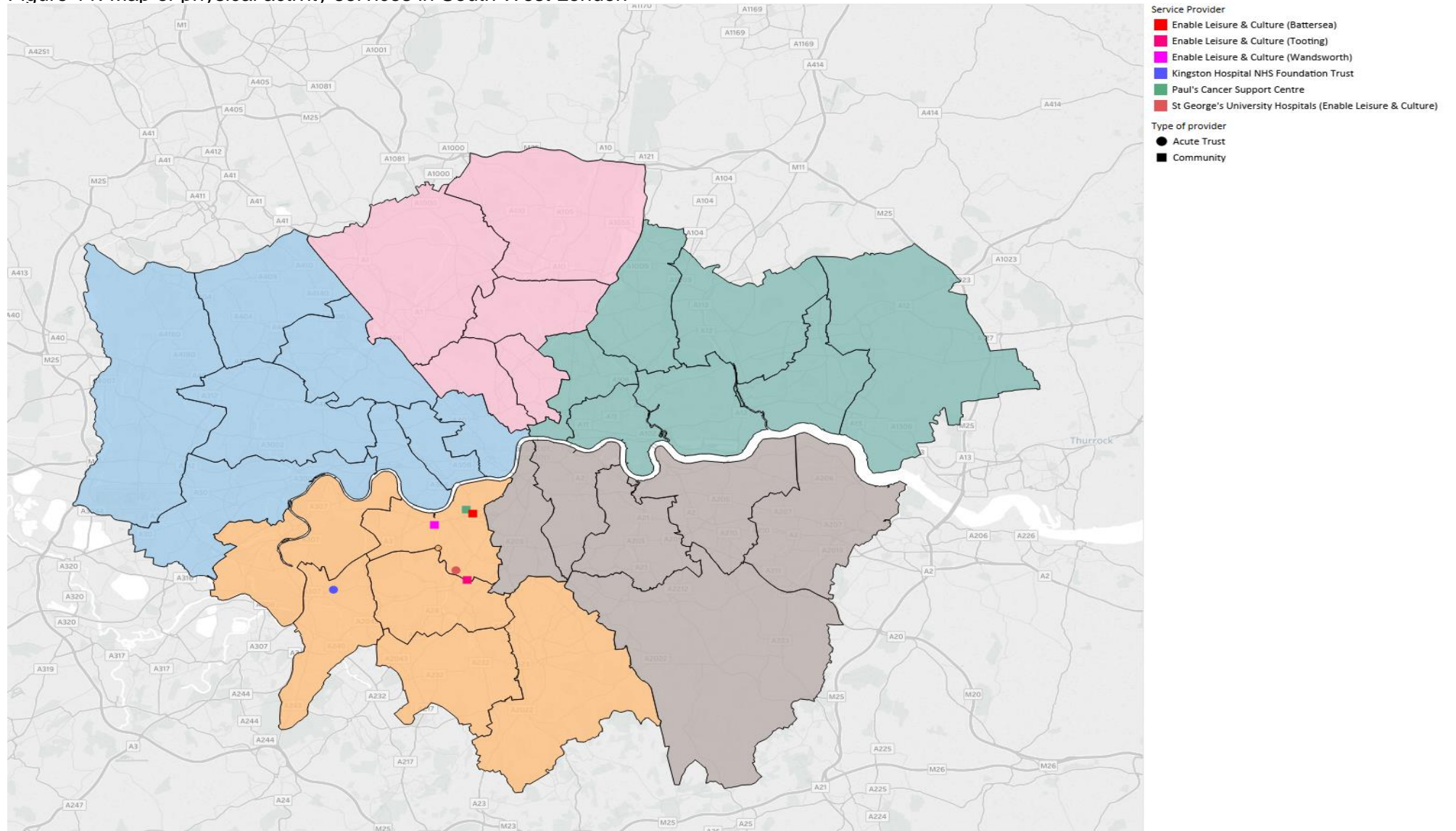
Epsom and St Helier NHS Trust provides cancer rehabilitation services through the general acute therapies team. This team delivers inpatient physiotherapy, speech and language therapy and occupational therapy. The trust also provides a specialist cancer dietetic clinic on each site.

Community and third sector

Royal Trinity Hospice in Hampstead offers physiotherapy services and a breathe better programme to help manage symptoms of breathlessness.

Physical activity services

Figure 11: Map of physical activity services in South West London



A range of physical activity programmes were reported across SWL:

Kingston Hospital NHS Foundation Trust delivers an exercise programme for breast cancer patients, which can be accessed six weeks after treatment, as well as a post cancer treatment exercise programme.

St George's University Hospitals NHS Foundation Trust and the **Tottenham Hotspurs Foundation** provide a Move4you programme, which is a 12-week structured exercise programme specifically designed for cancer patients.

Macmillan Move More Wandsworth provides cancer specific exercise classes as part of a physical activity behaviour change programme. These classes are delivered in Wandsworth, Merton and Sutton, in partnership with Enable Leisure & Culture.

Six Physio delivers tailored exercise programmes and pilates classes for cancer patients.

Paul's Cancer Support Centre provides cancer specific exercise classes through a trained level 4 instructor.

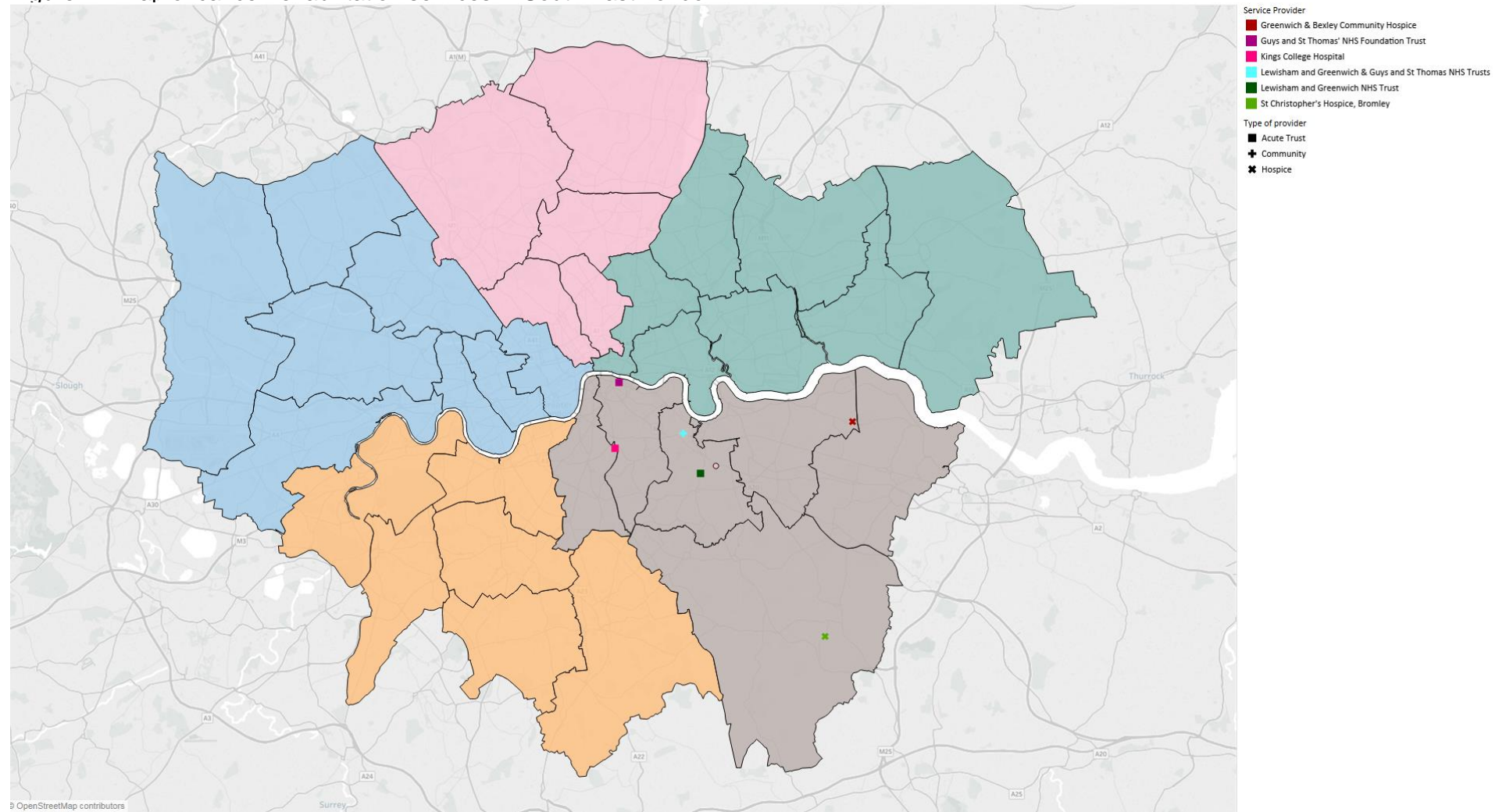
Royal Trinity Hospice runs seated exercise classes run by physiotherapists, as well as whole body workout exercise classes.

Trekstock provides the **Renew Exercise programme** for young adults, based at the Central YMCA, but open to referrals from across all London STPs. This is a 12-week exercise programme working with a Level 4 Cancer Rehabilitation qualified instructor to develop a tailored exercise plan, and is delivered by 1 to 1 gym-based sessions.

SOUTH EAST LONDON

Cancer rehabilitation services

Figure 12: Map of cancer rehabilitation services in South East London



Acute services

There was a range of provision of acute cancer rehabilitation services reported across South East London (SEL), with the majority of cancer specific services concentrated at **Guy's and St Thomas' NHS Foundation Trust**.

Guy's and St Thomas' NHS Foundation Trust provides a dedicated oncology rehabilitation facility within the Cancer Centre at Guy's hospital. This includes cancer-specific physiotherapy, dietetics, occupational therapy and speech and language therapy. Physiotherapy provision covers both inpatient and outpatient, as well as exercise pathways and classes.

Specialist dietetics oncology services are delivered for Head and Neck, Lung, Haematology, Teenagers and Young Adults (TYA) and Upper GI. Specialist dietetics delivers post-treatment weight management groups for cancer patients, and provides *Eat It Better* healthy eating classes for Teenagers and Young Adults, focusing on post-treatment diet.

The trust also provides occupational therapy for specialist oncology and haematology inpatients and outpatients services. In and outpatient Speech and Language Therapy is provided for specialist Head and Neck Oncology.

Outpatient rehabilitation clinics are provided within tumour specific clinics, including lung and neuro oncology. Early acute rehabilitation is provided in the following inpatient areas: neuro oncology, haem-oncology, thoracic surgery, upper GI surgery, acute oncology, head and neck cancer, Metastatic spinal cord compression pathway patients, palliative care services.

King's College Hospital NHS Foundation Trust provides physiotherapy as part of the brain, breast and haematology pathways, and occupational therapy as part of the haematology pathway. The rest of King's rehabilitation services are provided by general therapy teams. These include physiotherapy (for pathways other than brain and breast), dietetics, speech and language therapy and occupational therapy (other than haematology).

Lewisham and Greenwich NHS Trust provides general inpatient physiotherapy and inpatient occupational therapy, primarily focused on facilitating discharge.

Community and third sector

The Community Head and Neck (CHANT) Team is a multidisciplinary rehabilitation team comprised of head and neck cancer specialist dietitians, speech and language therapists, physiotherapists and clinical nurse specialists, providing rehabilitation and support to patients close to home. The team is a partnership arrangement, hosted by Lewisham and Greenwich NHS Trust, with clinical staff provided by Guys and St Thomas' NHS Trust. The team also receives support from psycho-oncology teams, and is the only service of their kind in the UK. Rehabilitation support is local community clinic based or domiciliary based, depending on patient need. The team works across all six

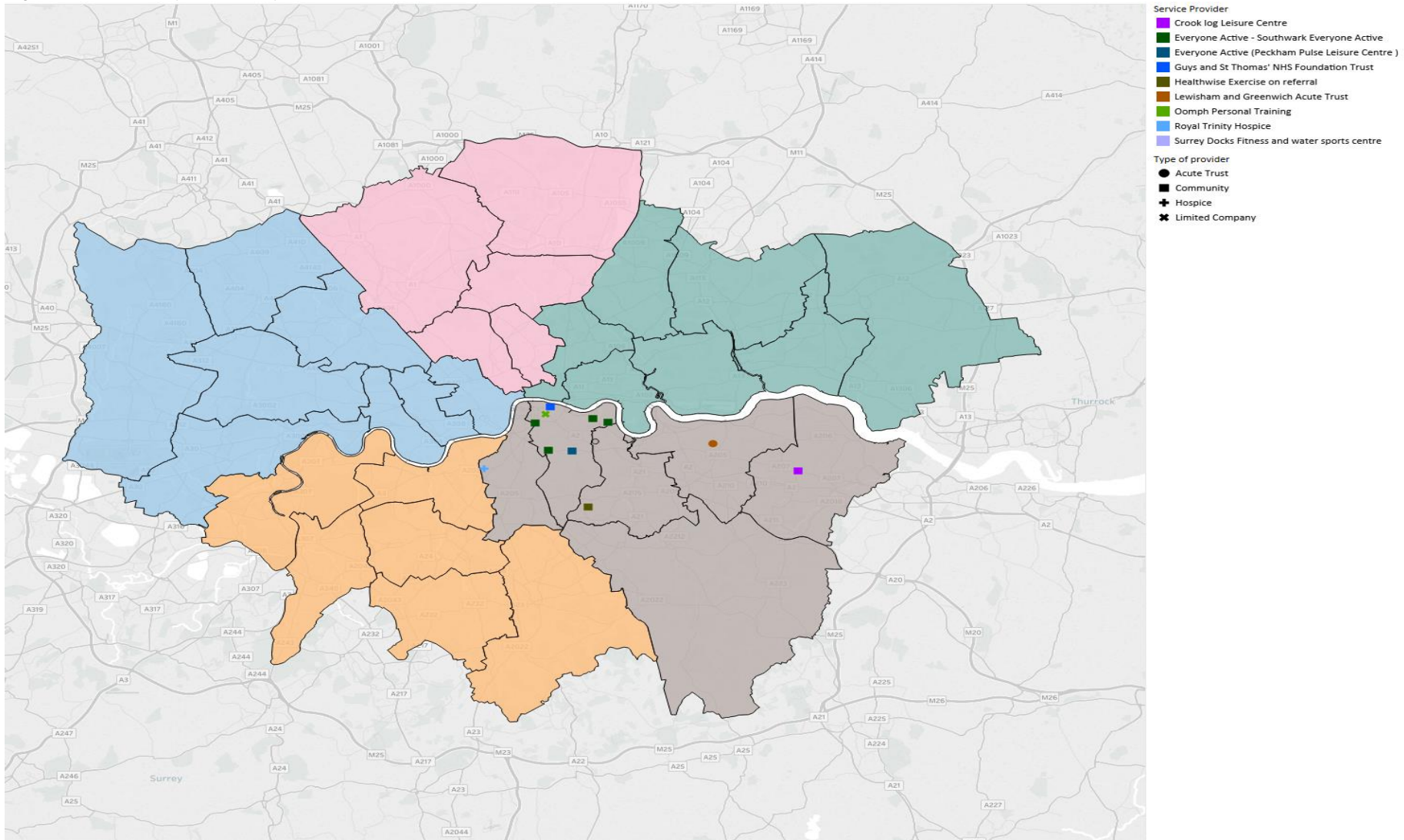
SEL CCGs. Provision is only for head and neck cancer patients, and there is no similar service for other pathways.

St Christopher's Hospice in Bromley offers physiotherapy, occupational therapy, dietetics and speech and language therapy.

Greenwich & Bexley Community Hospice offers physiotherapy services.

Physical activity services

Figure 13: Map of physical activity services in South East London



A range of physical activity programmes were reported across SEL.

Oomph Personal Training provides exercise programmes for cancer patients, working in partnership with third sector organisations, including Maggie's, and accepting patients on a referral basis.

Southwark Everyone Active is a GP referral exercise programme, which is not cancer specific, but which cancer patients can access. Level 4 trained instructors are trained by the Tottenham Hotspurs Foundation and provide a 12-week personalised exercise programme. Classes take place at several centres including Peckham Pulse Leisure Centre, the Castle Centre, Camberwell Leisure Centre, Dulwich Leisure Centre, Seven Islands Leisure Centre and Surrey Docks Fitness and Water Sports Centre.

Active Boost is an exercise on referral programme for people with long term conditions, including cancer. The programme is delivered at Surrey Docks Fitness and Water Sports Centre and provides 12 weeks of group exercise classes.

Steps to Health is a 12-week supervised group exercise class for those with long term conditions, including cancer. The programme is delivered at Crook Log Leisure Centre.

Healthwise Exercise on referral is a 12-week supervised group exercise class for people with long term conditions, which includes cancer, provided in Greenwich.

Lewisham provides an exercise referral scheme which includes a 12-week group exercise supervised gym class for those with a recognised long-term condition, of which cancer is included. The cost per session is £2.65. Lewisham also provides **Teach Sport**, which delivers a range of group activities including football and Zumba. The first 8 weeks are provided free of charge, and from £3.00 per session thereafter. These programmes are based from the Better Gym centres of Bellingham, Forest Hill, The Bridge, Wavelength and Glass Mill.

Guy's and St Thomas' NHS Foundation Trust runs physical activity sessions, both 1:1 and group sessions, which are tailored to individual need. Groups provide circuit programmes, mindful movement yoga classes, as well as weight management programmes and other education sessions.

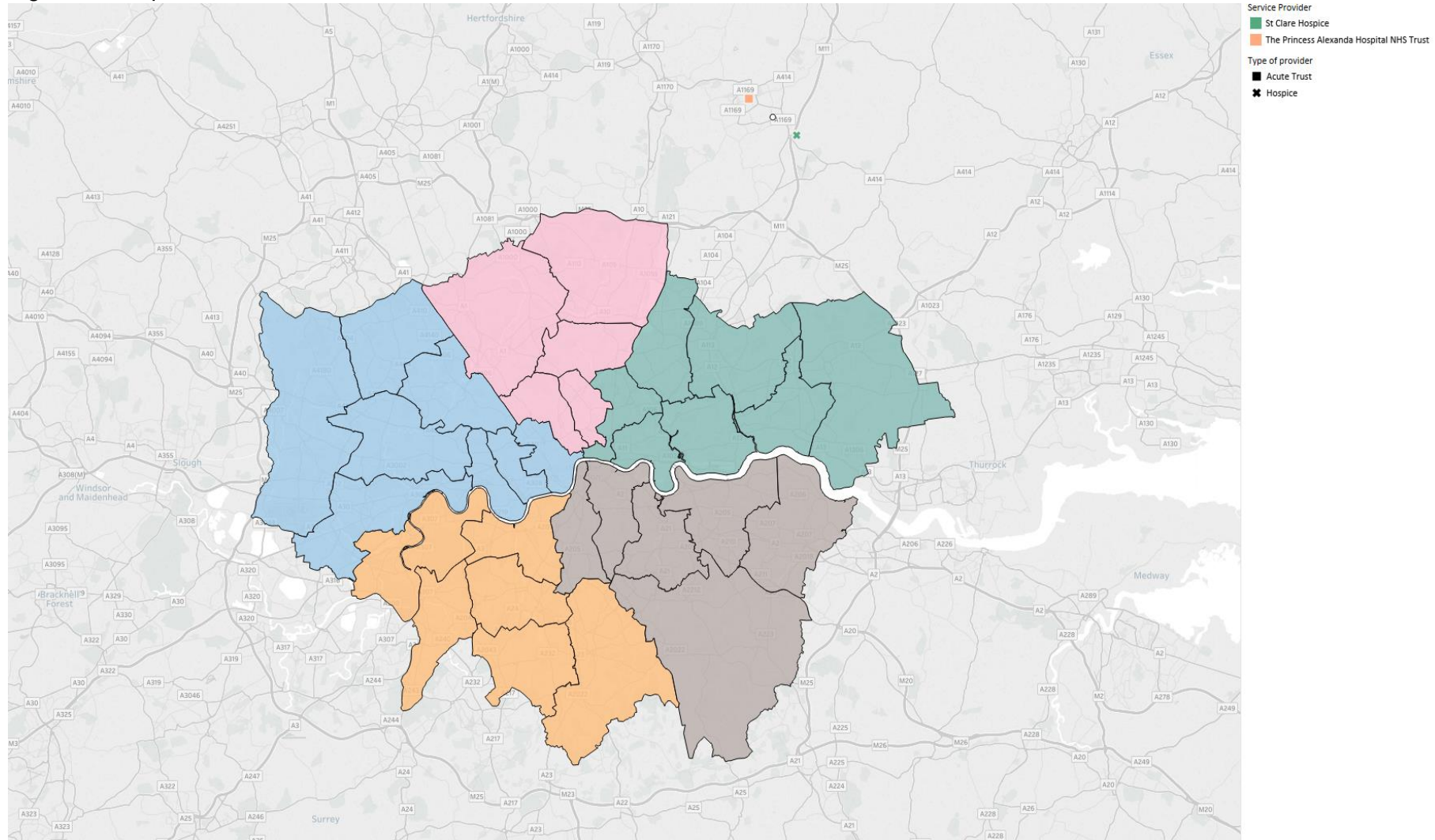
Lewisham and Greenwich NHS Trust delivers amputee exercise classes.

Trekstock provides the **Renew Exercise programme** for young adults, based at the Central YMCA, but open to referrals from across all London STPs. This is a 12-week exercise programme working with a Level 4 Cancer Rehabilitation qualified instructor to develop a tailored exercise plan, and is delivered by 1 to 1 gym-based sessions.

WEST ESSEX

Cancer rehabilitation services

Figure 14: Map of cancer rehabilitation services in West Essex



Acute services

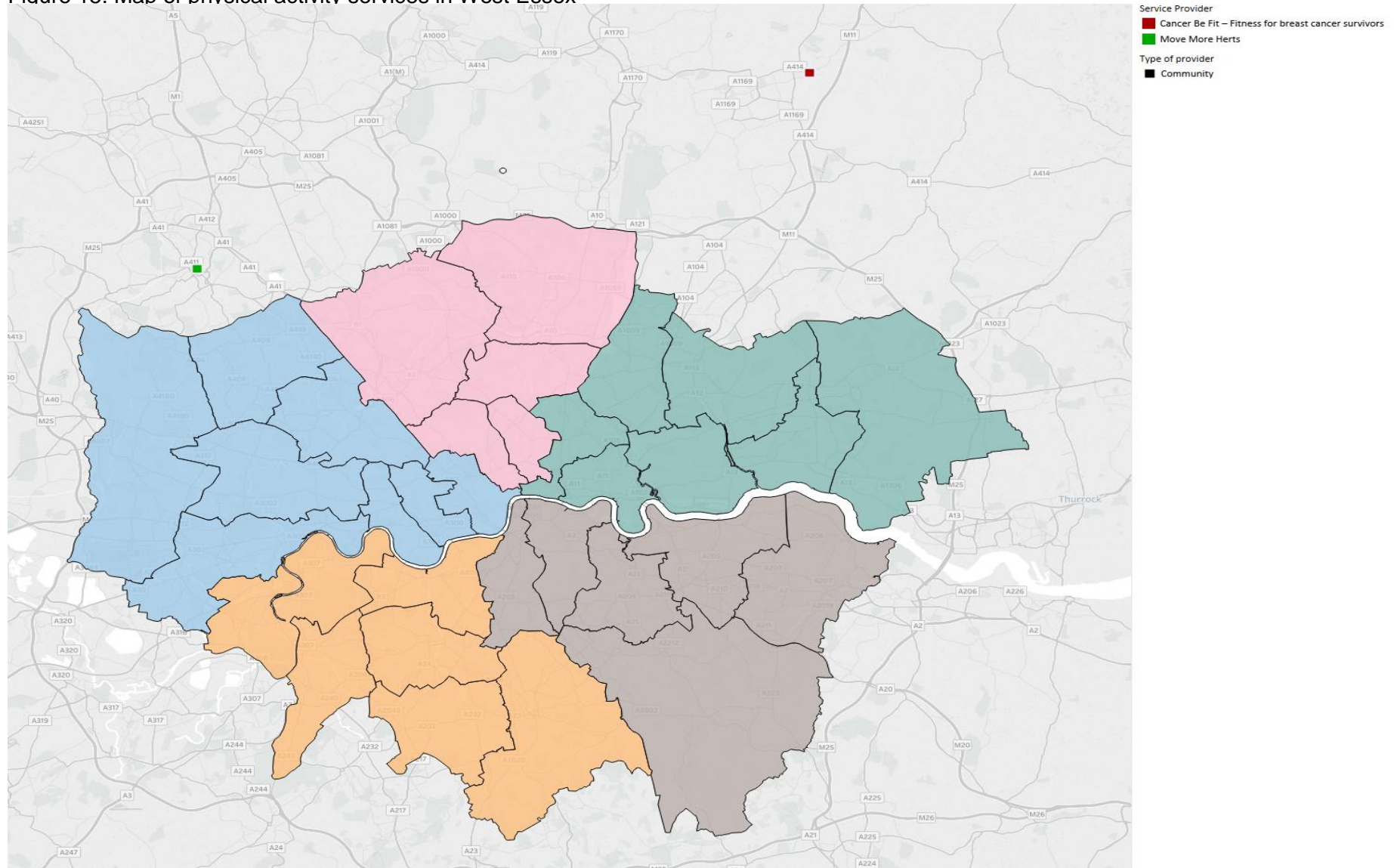
No response was received from the **Princess Alexandra Hospital NHS Trust**. Desk research suggests provision of general occupational therapy and dietetics services.

Community and third sector

St Clare Hospice offers inpatient and outpatient physiotherapy and occupational therapy.

Physical activity services

Figure 15: Map of physical activity services in West Essex



A limited range of physical activity programmes were reported across West Essex.

Move More Herts is an exercise programme for anyone affected by cancer, with the aim of helping them to become more active. The programme is delivered in partnership between Macmillan Cancer Support, YMCA, as well as Stevenage Leisure, Finesse Leisure and Broxbourne Leisure trusts. The programme is 12 weeks and fully funded, with further instructor guidance and support for an additional 12 months. Health and social care professionals can refer patients to the programme, and self-referral is also available.

Cancer Be Fit is a free to access fitness class for people who have been affected by breast cancer. The classes are provided by a qualified cancer and exercise rehabilitation specialists from Taylored Fitness.

The Asian Women Cancer Group provides weekly yoga classes for Asian women who have been affected by cancer.

Discussion of key findings

Key highlights

- Acute provision of cancer rehabilitation is relatively well spread; five STPs have specific provision for physiotherapy, occupational therapy, dietetics and speech and language therapy. West Essex has non-cancer specialist rehabilitation services. The extent of provision is variable with certain trusts providing a significant volume of cancer services, for example at Barts Health NHS Trust, The Royal Marsden NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust.
- There are significant gaps in access to cancer rehabilitation. For example, many services are only available for patients with certain tumour types and at certain points of the pathway.
- The most common barrier for cancer rehabilitation is funding. Some services highlighted the lack of growth in the cancer rehabilitation workforce. This has a significant impact on capacity and leads to gaps in service provision and unmet need.
- There are significant gaps in community provision for cancer rehabilitation services. South East London STP has a specialist head and neck cancer community team, with no provision for other pathways. The only community services found in the other five STP areas were those provided by hospices or third sector organisations. Gaps in community provision puts increased pressure on acute cancer rehabilitation services and so whilst acute services are relatively well spread, they are potentially struggling to meet demand. Furthermore, with a dependency on acute provision it is likely that few patients are being offered care close to home.
- Physical activity programmes for cancer patients are provided across all London STPs, but provision is variable. South East London has the highest number of services (n=9) with only two programmes in North West London. Programmes which are not cancer specific are also variable across the STPs.
- The main barrier for physical activity programmes was reported as funding (which traditionally comes from a range of sources including via CCGs, local authorities and the third sector). This was particularly so in the context of workforce provision. Service providers also noted a lack of awareness of their services, impacting referrals.

"My post only has funding to see Hepato-Pancreato-Biliary oncology and Upper Gastro Intestinal oncology and radiotherapy patients"

Cancer rehabilitation service

"Rehab services are under acknowledged and undervalued"

Cancer rehabilitation service

As part of this mapping exercise, services who were approached to complete the survey were also asked to identify the main barriers they consider to providing cancer rehabilitation care. The most frequently mentioned challenge was one of funding; it was

said that this contributed to long waiting times and insufficient staffing levels to meet patient need.

“We would like to offer a very responsive service but in an oncology hospital we cannot be in every clinic, so we need to target key areas”

Furthermore, some services noted that they were only funded to work with patients on certain tumour pathways, but that this was not representative of the breadth of patient need.

This was particularly highlighted in the context of developments in medical care/services without corresponding growth in cancer rehabilitation workforce. For example, in South East and South West London, it was felt that there had been a significant increase in demand for rehabilitation services following expansion of medical and/or nursing provision, presenting a significant challenge as the size of the rehabilitation workforce had not been developed.

Additionally, the challenge of recruiting specialist staff was also noted as a barrier in providing cancer rehabilitation services.

Some service providers noted the challenge in providing evidence of the long-term impact and outcomes of cancer rehabilitation, which would inform business case planning.

Service providers of physical activity programmes reflected many of the same barriers, but also suggested that there was a lack of awareness amongst health professionals both about the benefits of physical activity for cancer patients, and about the physical activity programmes which are available, which reduce the number of referrals.

“There is lack of awareness of physical activity benefits from all Health Professionals looking after cancer patients”

Commissioning cancer rehabilitation services providing cancer rehabilitation services

Whilst little intelligence was obtained with regards to how services are commissioned, previous work by TCST indicates a complex picture. AHP led services are usually commissioned in two main ways; via block contracts with CCGs and via charitable funding. Physical activity services are commissioned through local authorities and charitable funding.

Project limitations

The lack of detailed intelligence around how cancer rehabilitation services are commissioned presents a significant limitation of this mapping project. Furthermore, as there is no centralised source of all cancer rehabilitation services, it is not possible to ensure that all services who provide rehabilitation for those living with or beyond cancer have been included in this report, and it is acknowledged that there might be gaps present in this assessment.

Whilst the initial mapping took place between February and June 2018, there was a significant break before this was resumed in December 2018. This delay was due to loss of personnel in the project team. This delay might have had an impact on the data collected, and this is acknowledged as a possible limitation.

It proved extremely difficult to obtain intelligence about third sector and community cancer rehabilitation services. This report has not been able to map the potential services which primary care refers patients in to, which would potentially identify additional services. This was not possible in the time constraints of the mapping exercise and would require extensive resource.

This report also recognises limitations given the focus exclusively on the four main AHP groups (physiotherapists, occupational therapists, speech and language therapists and dieticians), and the physical activity programmes. We recognise the important role that other AHPs and other health professionals e.g. nursing and psychological support services as well other services such as social prescribing, play in the rehabilitation of people living with and beyond cancer. Due to the limited scope of our report, these were not included in this mapping exercise. Furthermore, this process has not produced evidence of many prehabilitation services, which subsequent desk research has indicated are provided in some areas.

This report has also excluded lymphoedema services and questions around workforce, as these are areas which have been mapped previously and which are being refreshed in Autumn 2019 by the three Cancer Alliances and the Lymphoedema Community of Practice. As part of the recommendations of this report, the data obtained in this publication will be triangulated with further data as it becomes available.

All information contained in this report was correct at the time of publication.

Recommendations

Phase one – (2019/2020)

1.1. TCST and London based Cancer Alliances to triangulate data from this report with upcoming workforce data available through Alliance led mapping (due Autumn 2019), and will make recommendations regarding rehabilitation provision/commissioning improvements to the London Cancer Commissioning Board.

1.2. All CCGs and STPs to build on the momentum of ongoing system reconfiguration (in the context of developing Integrated Care Systems and Primary Care Networks), and work collaboratively to

- examine the commissioning, provision of and access to, cancer rehabilitation locally; and
- develop an action plan for improvement in personalised care provision

1.3. STPs, Cancer Alliances and Macmillan to work in partnership with local cancer rehabilitation services and voluntary services to implement the TCST service improvement tools (available [here](#)), to support service development and improvement, as well as to collect quality baseline data, in line with the TCST data recommendation report (available [here](#))

Phase two – (2020 - 2023)

2.1. Building on recommendations 1.2 and 1.3, CCGs and STPs to work collaboratively with key partners (including non-cancer services, the voluntary sector, primary care networks and Integrated Care Systems) to implement improvements to ensure provision of comprehensive cancer rehabilitation at the appropriate level for **all cancer patients, across all tumour groups and at every stage of the pathway**, including prehabilitation and palliative rehabilitation.

2.2. Providers to commit to developing rehabilitation services in line with increasing numbers of people diagnosed with cancer, relevant developments in medical care provision, as well as advancements in medical treatment, adapting to provide timely and high-quality services in line with changing demands.

Project support

This project was supported by a Task and Finish Group comprising of:

- Georgina Wiley, Macmillan Project Facilitator, Transforming Cancer Services Team (TCST) – Project Lead (January 2018 – June 2018)
- Ashley Bowcock, Project Co-ordinator, South East London Accountable Cancer Network
- Roxanne Payne, Project Coordinator for Macmillan Integrated Cancer Programme, UCLH Cancer Collaborative
- Mary Tsikata, Macmillan Senior Project Support - Living With and Beyond Cancer, RM Partners
- Sophie Lansdowne, Macmillan Project Manager, Transforming Cancer Services Team (TCST) – Project lead and final report author (November 2018 – April 2019)

All project work was overseen by a Steering Committee which was chaired by:

- Dr Karen Robb, Rehabilitation Clinical Lead, TCST – lead for the Cancer rehabilitation work stream

Other members of the Steering Committee are provided in Appendix A.

In addition, the following people were instrumental in completing this piece of work:

- Vanessa Brown, Macmillan Project Manager LWBC, RM Partners
- Amanda Shewbridge, Macmillan Nurse Programme Manager for Living With and Beyond Cancer, South East London Accountable Cancer Network
- Sharon Cavanagh, Lead for Macmillan Integrated Cancer Programme, Living with and Beyond Cancer and Allied Health Professionals, UCLH Cancer Collaborative
- Chipso Chirewa, Cancer Intelligence Lead, TCST - visual mapping

Acknowledgements

TCST would like to thank the Task and Finish Group for all their work and support. TCST would also like to thank all the services that took the time to provide information through online surveys and follow up discussions. Your support is greatly appreciated.

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List of Appendices

- **Appendix A:** Steering Committee Members overseeing the project (provided on **Page 51**)
- **Appendix B:** Template Survey for service providers (provided on **Page 52**)
- **Appendix C:** Template Survey for commissioners (provided on **Page 57**)
- **Appendix D:** All mapped physical activity services (available as a downloadable pdf files [here](#))
- **Appendix E:** All mapped cancer rehabilitation services (available as a downloadable pdf files [here](#))
- **Appendix F:** Interactive map of all cancer rehabilitation and physical activity services (available [here](#)).

Appendix A: Steering Committee Members overseeing the project

| | | |
|---|--|--|
| Dr Karen Robb (KR) Chair | Macmillan Rehabilitation Clinical Lead | TCST |
| Sharon Cavanagh (SC) | Lead for the Macmillan Integrated Cancer (MICA) Programme, Living with and Beyond Cancer and Allied Health Professionals | UCLH Cancer Collaborative |
| David Jillings (DJ) | Trustee, the Pelvic Radiation Disease Association | PRDA |
| Jason Petit (JP) | Senior Cancer Intelligence Lead | TCST |
| Dr Claire Taylor (CT) | Macmillan Nurse Consultant in Colorectal Cancer | London North West Healthcare NHS Trust |
| Lindsay Farthing (LF) | Clinical Lead for Oncology Therapies | Barts Health NHS Trust |
| Samantha Tordesillas (ST) | Clinical Team Lead | SEL Community Head and Neck Cancer Team |
| Karen Turner (KT) | Service and Clinical Lead Physiotherapist | Royal Free London NHS Foundation Trust |
| Kate Ashforth (KA) | Joint Head of Speech and Language Therapy | The Royal Marsden NHS Foundation Trust |
| Bianca Karpf (BK) and Laura Westwick (LW) | Macmillan Social Prescribing Manager | Bromley by Bow Centre |
| Siobhan Cowan-Dickie (SCD) | Clinical Specialist Physiotherapist, Living With and Beyond Cancer | Royal Marsden Hospital NHS Trust |
| Philippa Hyman (PH) | Macmillan Mental Health Clinical Lead and Clinical Psychologist | TCST |
| Yvonne Damanhuri (Minute Taker) | TCST Administrator | TCST |
| June Davis (JD) | National Cancer Rehabilitation Lead | Macmillan Cancer Support |
| Dawn Secker (DS) | Corporate Head of Service Kingston and New Malden Locality and Principal Social Worker | Royal Borough of Kingston upon Thames |
| Amanda Shewbridge (AS) | Macmillan Nurse Programme Manager for Living With and Beyond Cancer | South East London Accountable Cancer Network |
| Vanessa Brown (VB) | Senior Macmillan Project Manager - Living with and beyond Cancer | RM Partners |
| Viki Bainsfair (VB) | Health & Wellbeing Manager | YMCA Thames Gateway |
| Katherine Kavanagh (KK) | Cancer Commissioning Manager – BHR & West Essex | NEL CSU |
| Neil Burley (NB) | Therapy Radiographer/Proton lead | University College London Hospital |
| Sophie Lansdowne (SL) | Project Manager – Personalised Care for Cancer | TCST |

Appendix B: Template Survey for service providers

Please note: this is written version of the electronic version provided via the online platform, Survey Monkey.



Transforming Cancer Services Team Rehab Mapping

Questions for services providing rehabilitation services to those with cancer

Introduction

In 2016 a scoping project was undertaken by the Transforming Cancer Services Team (TCST) to better understand the services providing rehabilitation to those with cancer in London and to inform the development of future commissioning guidance for cancer rehabilitation. TCST engaged with multiple stakeholders and the work was fully funded by Macmillan Cancer Support.

This scoping project demonstrated

- The lack of good data on cancer rehabilitation services
- Poor awareness and understanding of the breadth and scope of cancer rehabilitation
- There are significant gaps in services providing rehabilitation for those with cancer There is evidence that these gaps negatively impact on patient care.

This survey is designed to identify those services that are providing rehabilitation to those with cancer the results of which will inform comprehensive cancer rehabilitation commissioning guidance currently being developed. This service mapping will include NHS and third sector services commissioned by the NHS, the local contracting arrangements with commissioners, and level of need across London CCGs (acute, community, voluntary organisations).

We are collecting information on:

- What is the service and where is it located
- Access to the service
- What is provided within the service
- Commissioning
- Evaluation and Quality Assurance of the service

It is anticipated that this survey will take no more than 15 minutes to complete.

For more information about this mapping exercise, if you have any comments or feedback or if you are having trouble completing this form please contact:

Georgina Wiley (lead) – Macmillan Project Facilitator, Transforming Cancer Services Team for London Georgina.Wiley@nhs.net

What is the service?

1. Does your service provide a rehabilitation service for people with cancer?

If no – please do not continue to fill in this form

Yes

No

2. Please state the title/name of your service (free text)

This question refers to the title or name of the service you are filling in this survey for

3. Please state the name of the service provider (free text)

Please list the acute trust/community service etc. who provides this service

4. Please provide the name and contact details of person filling out this form

5. Provider type

NHS

Other (add details)

Voluntary

Local Authority

6. Summary of service

Please select all that apply and list others that you feel may be relevant in the 'other' space

Community

Secondary care inpatient

Tertiary/specialist inpatient

Home

Hospice

Primary care

Secondary care outpatient

Tertiary/specialist outpatient

Cancer specific

Other (add details)

.....

7a. How would you describe the objective of your service?

Please select all that apply and list others that you feel may be relevant in the 'other' space

The Recovery Package is a set of essential interventions designed to deliver a person centred approach to care for people affected by cancer. This includes: Holistic Needs Assessment (HNA) and care planning, Treatment Summary (TS), Health and wellbeing events and Cancer care review (CCR). For more information please click here: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package>

Advising on self-management

Making referrals to other health professionals

Healthy lifestyle groups

Signposting to other healthcare providers, sectors or settings

| | |
|--|---|
| Supporting those with side effects or consequences of treatment | Delivering interventions for patients with advanced disease, complex palliative /end of life issues |
| Delivering interventions for patients with functional impairment | Supporting families of carers |
| Delivering interventions for patients with cognitive impairment | Delivering interventions during or after treatment |
| Delivery of the recovery package | |
| Other (add details) | |

7b. If your service is involved with the recovery package please indicate which aspects?

| | |
|---|--------------------------|
| Holistic Needs Assessment (HNA) and care planning | Treatment Summary (TS) |
| Health and wellbeing events | Cancer care review (CCR) |
| N/A | |

Where is the service based?

8. Catchment area

Please tick all London Boroughs that your service covers. For more information on CCG's in the NHS London region please click here: <https://www.england.nhs.uk/london/ccg-trust/>

If your service covers areas outside of the London remit (e.g. Kent, Surrey) please indicate these in the 'other' section

- Barking and Dagenham
- Barnet
- Bexley
- Brent
- Bromley
- Camden
- Central London (Westminster)
- City and Hackney
- Pan-London
- Croydon
- Ealing
- Enfield
- Greenwich
- Hammersmith and Fulham
- Haringey
- Harrow
- Havering
- West Essex
- Hillingdon
- Hounslow
- Islington
- Kingston
- Lambeth
- Lewisham
- Merton
- Newham
- Other (please provide details) :
- Redbridge
- Richmond
- Southwark
- Sutton
- Tower Hamlets
- Waltham Forest
- Wandsworth
- West London (Kensington and Chelsea)

Who can and how can they access service?

9. At what stage of treatment do you accept/see cancer patients (please select all that apply)

Please provide any additional information you feel is relevant in the comments section

| | | | |
|---|-----------|----------------|-----------------|
| Diagnosis and care planning End of life | Treatment | Post treatment | Palliative care |
|---|-----------|----------------|-----------------|

10. Please indicate waiting time for access to your service. Are there variables to this (time of year etc.)?

Please indicate any known variables (e.g. holiday periods etc.) in the comments section below

| | |
|-----------------------|------------|
| Less than 1 month | 1-3 months |
| Greater than 3 months | |
| Comments | |

11. How many patients would the service see annually? Of these what percentage are cancer patients? (Please provide an estimate If you do not know exact figures)

As we are mapping cancer rehabilitation services the percentage of cancer patients being seen by your service is important for us to collect to be able to paint a complete picture.

12. Of these what percentage are cancer patients? (Please provide an estimate If you do not know exact figures)

| | |
|--------|---------|
| 0-25% | 51-75% |
| 26-50% | 76-100% |

As we are mapping cancer rehabilitation services the percentage of cancer patients being seen by your service is important for us to collect to be able to paint a complete picture.

13. How are cancer patients referred to your service? (Please select all that apply)

| | |
|-----------------------------|---|
| Self-Referral | Invitation by health care professional |
| Health Care professional | Either Self Refer or HCP |
| Other | |

What is provided within service?

14. What type of service do you provide? (Please select all that apply)

| | |
|-----------------------|-----------|
| 1 to 1 | Telephone |
| Clinic | Skype |
| Drop-in | Email |
| Group | Other |
| Couples and/or family | |

15. What would you identify as the top challenges of the service to achieve its aims and outcomes for cancer patients?

Please list other challenges you identify in the other section.

Lack of funding

Long wait times

Too many patients

Not available to carers

Not enough staff

Not cancer specific

Staff recruitment

Staff skill shortage

Lack of education and training for staff

Other (please specify)

How is service commissioned?

16. Who is responsible for engaging with commissioners regarding your service? (please provide name, role and contact details of this person) (Free Text)

17. Who commissions your service? Please provide contact details (Free Text)

If you are not aware of how your service is commissioned please (a) attempt to find out before completing this survey or (b) state 'I don't know'. If your service is not clearly commissioned please provide details on this.

Evaluation

18. Do you use a measure/s to evaluate change in patients seen by your service?

Yes

No

Details:

Other

19. What are the top 5 services you routinely refer patients into?

Please provide name and contact details if known

20. Is there a type of service not available which you would like to be able to refer to?

21. Any additional information you feel it is important for us to know?

Thank you for your time!

Appendix C: Template Survey for commissioners

Please note: this is written version of the electronic version provided via the online platform, Survey Monkey.



Healthy London
Partnership

Transforming Cancer Services Team

The mapping of services that provide rehabilitation to those with cancer

Questions for Commissioners

Introduction

In 2016 a scoping project was undertaken by the Transforming Cancer Services Team (TCST) to better understand the services providing rehabilitation to those with cancer in London and to inform the development of future commissioning guidance for cancer rehabilitation. TCST engaged with multiple stakeholders and the work was fully funded by Macmillan Cancer Support.

This scoping project demonstrated

- The lack of good data on cancer rehabilitation services
- Poor awareness and understanding of the breadth and scope of cancer rehabilitation
- There are significant gaps in services providing rehabilitation for those with cancer There is evidence that these gaps negatively impact on patient care.

This survey is designed to identify those services that are providing rehabilitation to those with cancer the results of which will inform comprehensive cancer rehabilitation commissioning guidance currently being developed. This service mapping will include NHS and third sector services commissioned by the NHS, the local contracting arrangements with commissioners, and level of need across London CCGs (acute, community, voluntary organisations).

We are collecting information on:

- What is the service and where is it located
- Access to the service
- What is provided within the service
- Commissioning
- Evaluation and Quality Assurance of the service

It is anticipated that this survey will take no more than 15 minutes to complete.

For more information about this mapping exercise, if you have any comments or feedback or if you are having trouble completing this form please contact:

- Georgina Wiley (lead) – Macmillan Project Facilitator, Transforming Cancer Services Team for London Georgina.Wiley@nhs.net

What is the service?

1. Please state the title/name of the service (free text)

This question refers to the title or name of the service you are filling in this survey for

2. Please state the name of the organisation service provider (free text)

Please list the acute trust/community service etc. who provides this service

3. Please provide the name and contact details of person filling out this form (and please indicate if you are happy to be contacted post survey completion if necessary) (free text)

4. Who is your named contact at the service? (who do you go to with questions etc.) (free text)

5. Is there a service specification?

Yes

No

Don't know

Details:

6. Provider type

| | |
|----------------------------|-----------------------------------|
| NHS | <i>Voluntary and third sector</i> |
| <i>Other (add details)</i> | <i>Local Authority</i> |

7. Summary of service

Please tick all that apply and list others that you feel may be relevant in the 'other' space

| | |
|--------------------------------------|---------------------------------------|
| <i>Community</i> | <i>Primary care</i> |
| <i>Secondary care inpatient</i> | <i>Secondary care outpatient</i> |
| <i>Tertiary/specialist inpatient</i> | <i>Tertiary/specialist outpatient</i> |
| <i>Home</i> | <i>Other (add details)</i> |

Hospice

Other

.....
Yes/No

8. Is the service cancer specific?

Yes

No

Don't know

Comment

9. Is the service based within the CCG boundaries?

Yes

No

Don't know

10. As a commissioner, how would you describe what the service does?*Please select all that apply and list others that you feel may be relevant in the 'other' space*

| | |
|--|---|
| Advising on self-management | Healthy lifestyle groups |
| Making referrals to other health professionals | Signposting to other healthcare providers, sectors or settings |
| Supporting those with side effects or consequences of treatment | Delivering interventions for patients with advanced disease, complex palliative /end of life issues |
| Delivering interventions for patients with functional impairment | Supporting families of carers |
| Delivering interventions for patients with cognitive impairment | Delivering interventions during or after treatment |
| Delivery of the recovery package | Other (add details) |

Access to service**11. At what stage does the service accept/see cancer patients (please tick all that apply)***Please provide any additional information you feel is relevant in the comments section*

| | | | |
|------------------------------------|------------------|-----------------------|------------------------|
| <i>Diagnosis and care planning</i> | <i>Treatment</i> | <i>Post treatment</i> | <i>Palliative care</i> |
| <i>End of life</i> | | | |

12. Please indicate the average waiting time for a new patient to be seen by the service if known Are there variables to this (time of year etc.)?*Please indicate any known variables (e.g. holiday periods etc.) in the comments section below*

| | |
|------------------------|------------|
| Less than 1 month | 1-3 months |
| Greater than 3 months | Not known |
| Comments and variables | |

13. How many patients would the service see annually? Of these what percentage are cancer patients? (please provide an estimate If you do not know exact figures)*As we are mapping cancer rehabilitation services the percentage of cancer patients being seen by your service is important for us to collect to be able to paint a complete picture.***14. How are cancer patients referred to the service? (Please select all that apply)**

| | |
|--------------------------|--|
| Self-Referral | Invitation by health care professional |
| Health Care professional | Either Self Refer or HCP |
| Other | |

What is provided within service?

15. What type of service is provided? (Please select all that apply)

| | |
|-----------------------|-----------|
| 1 to 1 | Telephone |
| Clinic | Skype |
| Drop-in | Email |
| Group | Other |
| Couples and/or family | |

16. Does your CCG commissions the Recovery Package as part of the service offered by the services providing rehabilitation to those with cancer team?

The recovery package has been part of commissioning intentions for last 5 years and is a set of essential interventions designed to deliver a person centred approach to care for people affected by cancer. This includes: Holistic Needs Assessment (HNA) and care planning, Treatment Summary (TS), Health and wellbeing events and Cancer care review (CCR). For more information please click here: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package>

- Yes
- No
- Don't know

17. If yes please select which aspects it is involved in (if known): Please tick all that apply

| | |
|---|--------------------------|
| Holistic Needs Assessment (HNA) and care planning | Treatment Summary (TS) |
| Health and wellbeing events | Cancer care review (CCR) |

How is service commissioned?

18. How is the rehabilitation service commissioned? Please provide details of who and how the service is commissioned (including duration, costs and patient numbers)

19. When is the review date for commissioning of this service?

Evaluation/Quality Assurance

20. How is the service evaluated? Do you have any reports you can link us to?

21. How does the rehabilitation service measure:

- **Clinical Effectiveness**
- **Patient Safety**
- **Patient Experience**
- **Safeguarding**

Other

22. Any additional information you feel it is important for us to know?

Thank you for your time!