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Integrated Care System Guidance for Cancer Rehabilitation

A guide to reducing variation and improving
outcomes in cancer rehabilitation in London

Effective: April 2019

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Forewords

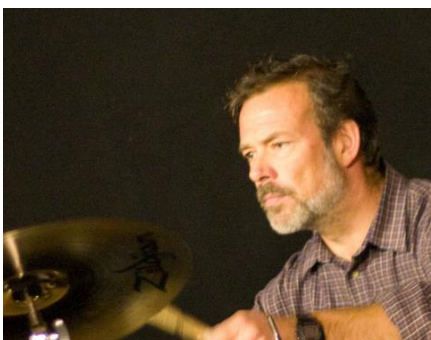


Steve Tolan, Allied Health Professions Lead, NHS England (London Region)

This *Integrated Care System Guidance for Cancer Rehabilitation* is published in the early stages of the 10-year NHS Long Term Plan. This plan re-states the commitment of the NHS to support people from earlier diagnosis, through their cancer treatment journey and beyond. This includes providing personalised care and giving greater attention to quality of life.

We know that one in two of the London and West Essex population are likely to be diagnosed with cancer in their lifetime. The NHS Long Term Plan includes commitments to improve early diagnosis and continue increases in long term survivorship. However, there is also a need to ensure that service users are supported to manage the impact of their cancer and their survivorship journey. The Transforming Cancer Services Team (TCST) has identified that access to rehabilitation has an essential role in supporting people to achieve their treatment and survivorship goals.

As the demand for cancer services continues to increase, this much needed guidance aims to reduce the unwarranted variation in access and quality of cancer rehabilitation across London and West Essex. The TCST team have identified what good looks like and how commissioners can work with providers to ensure their local populations have access to the rehabilitation services they need. Together, there is an opportunity to ensure that those having to experience a cancer diagnosis do not just live longer, but are supported to live well too.



David Jillings, trustee, Pelvic Radiation Disease Association

Rehabilitation has for a long time been Cinderella at the cancer ball, often relying for funding on a fairy godmother in an NHS hospital trust, or the charitable sector. Unsurprisingly, the availability of all the necessary services is patchy. There are many excellent rehab providers, but most of these stand isolated.

Is there even one part of London where every cancer patient can have the full spectrum of their needs addressed, from pre-treatment until as long afterwards as it is needed, holistically encompassing physical, financial and emotional needs, and involving family and carers, multi-disciplinary teams, and family doctors?

The evidence gathered by TCST and others in the preparation of this guidance suggests not. Even if there is, it is likely that no single service is aware of all the others. This

means the patient cannot be signposted towards them. The questions asked during the development of this guidance, which involved over one hundred hours of face-to-face time with patients, and even more with service providers, confirmed that there are needs which are not being met. TCST also uncovered gaps that had not been anticipated.

Most rehabilitation services recognise that more should be done, and have welcomed any opportunity to discover where improvements can be made. It has been extremely encouraging to see such a positive approach from hard-pressed services. But it remains the case that no amount of guidance or best practice is a substitute for resources, and if rehabilitation services are not properly commissioned there will always be gaps. Without this, excellent treatment will remain a postcode lottery, or the result of happenstance.

One thing we know for sure is that the number of patients treated for cancer will increase, and survival rates will improve as well. This will result in significant increase in demand for rehabilitation. We owe it to patients to give them the best possible chance of dealing with the impacts of their treatments, and of enjoying the best possible quality of life afterwards. They deserve world-class cancer rehabilitation commissioning. The recommendations in this report will make a worthy contribution towards achieving that goal.

It has been a pleasure to work with the TCST team, and the healthcare professionals and other experts who have assisted them. Compiling this report has taken a tremendous amount of effort, and on behalf of those who will unfortunately find themselves needing support during their experience of cancer, I thank everyone involved, and look forward to seeing the next phases of this work.

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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.

Our pan-London transformation will be **responsible** for:

- A 'once-for-London' approach to implementing the NHS Long Term Plan
- Providing subject matter expertise, evidence and intelligence for cancer commissioning support
- Working with partners to reduce variation and deliver improved cancer outcomes
- Primary care development and education
- Targeted service improvement in secondary care

About this document

Rehabilitation is a vital component in the care of people living with and beyond cancer and is key to delivering personalised care. Cancer rehabilitation provides a range of benefits for the wider healthcare economy, but more needs to be done to raise the profile and awareness of cancer rehabilitation in London.

This Integrated Care System Guidance for Cancer Rehabilitation was produced by TCST and fully funded by Macmillan Cancer Support. It aims to reduce variation and improve outcomes across London, and ensure that all patients living with and beyond cancer have access to rehabilitation at all key stages of the cancer pathway. The guidance includes an overview of cancer rehabilitation services in London and West Essex, service improvement tools outlining what good looks like, and a minimum dataset. A range of recommendations are presented alongside the next steps needed to support implementation.

Executive summary

Rehabilitation is a vital component in the care of people living with and beyond cancer and is part of the Cancer Taskforce recommendations. It is likely that demand for services will grow as our population ages, and more people survive cancer and live with the consequences of their cancer treatment. Previous work by the Transforming Cancer Services Team has shown that cancer rehabilitation is highly valued by patients and carers, and improving access to, and knowledge about services is a priority. Despite the importance of cancer rehabilitation for people and populations, there are many challenges facing services in London. We know that more needs to be done to raise the profile and awareness of cancer rehabilitation in London and outline the vital role it plays across every cancer pathway.

The publication of the NHS England 'Long Term Plan' has highlighted the importance of an all age, whole population approach to personalised care. Empowering people and supporting them to build knowledge, confidence and skills, and to stay well within their communities, is central to the model of personalised care. Rehabilitation plays a vital role in delivering this vision. In addition, rehabilitation services support the integrated care agenda and provide a range of benefits for the wider healthcare economy; most notably by keeping patients out of hospital, supporting early discharge and providing care closer to home. Rehabilitation is vital in supporting economic efficiencies across the NHS, therefore investing in rehabilitation makes sound economic sense.

Our work in lymphoedema and psychosocial support has shown the benefits to patients and the wider healthcare system of producing commissioning guidance with clear recommendations and an accompanying work-plan to support implementation. This guidance aims to reduce variation in cancer rehabilitation across London and West Essex, and improve the commissioning of services through better understanding of what good looks like, what is currently available, and how providers can be supported with service development. Work to produce this Integrated Care System Guidance for Cancer Rehabilitation was fully funded by Macmillan Cancer Support between April 2016 and April 2019, and led by Dr Karen Robb the Macmillan Rehabilitation Clinical Lead for TCST. This work was overseen by a multi-disciplinary Steering Committee and the patient voice has been central to all discussions and decisions. Three 'task and finish' groups were established to carry out the project and work was focused in 3 main areas; mapping of cancer rehabilitation services, creation of a minimum dataset and development of service improvement tools.

- 1) Mapping of services:** A comprehensive mapping of adult cancer rehabilitation services in London and West Essex was undertaken. Our full report is available [here](#) and should be read alongside this guidance. Although the provision of AHP led cancer rehabilitation is relatively well spread across the five STPs in London, there remain significant gaps in access, particularly in community settings. A similar picture exists for physical activity services. The biggest challenge experienced by providers is lack of funding and workforce constraints. It has not

been possible to gather detailed information on how cancer rehabilitation services are being commissioned. More work is needed to triangulate findings from this work with the workforce mapping led by the Cancer Alliances, which is due for completion in Autumn 2019.

- 2) **Minimum dataset:** TCST developed, piloted and socialised a minimum dataset for cancer rehabilitation services that has significant potential to reduce variation in service provision across London. Our full report is available [here](#). The dataset is designed to be collected by clinicians and has a wide range of benefits for commissioners, service providers and service users. There are significant challenges in implementing this dataset and work is on-going with a wide range of partner organisations to further develop this work. In addition, TCST and Macmillan Cancer Support have created a patient facing questionnaire designed to capture essential basic information about users' experience of using cancer rehabilitation services and the outcomes of care. This questionnaire is being hosted on the Macmillan electronic Holistic Needs Assessment (e-HNA) portal and will undergo a UK wide 6-month evaluation. This work has significant potential to further our knowledge of the use of cancer rehabilitation services in London (and nationally) and to influence decision-makers around the importance of good data.
- 3) **Service improvement tools:** These tools outline a clear framework for what good cancer rehabilitation looks like and what is needed for proactive, personalised, accessible and coordinated care to be delivered. They have a range of uses including: raising the profile of rehabilitation services with senior managers, engaging with commissioners, undertaking service development activities and demonstrating patient centred care. The tools have been developed through extensive stakeholder engagement and evidence building activities and have been well received by providers. A full report is available [here](#) and the tools are available [here](#).

Recommendations

1) Mapping

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.

2) Minimum dataset

2019/2020

- Cancer Alliances to support TCST and Macmillan in the collection of cancer rehabilitation data on the eHNA portal.
- Commissioners and Cancer Alliances to work in partnership with TCST and local cancer rehabilitation services to collect quality baseline data, in line with the TCST data recommendation report.

3) Service improvement tools

Phase one – 2019/2020

- Embed the service improvement tools into clinical practice. This will require endorsement from CCGs, STPs, Alliances and continued support from TCST for implementation.

- Cancer rehabilitation services to meet with senior managers/local commissioners to speak about their experiences with the tools, and about service improvement opportunities they have identified through the process

Phase two – 2020 and beyond

- As a next phase of this work, the tools could be used to allow benchmarking between services. This would require infrastructure that can support this, such as the NHS Improvement Model Hospital.

4) Other integrated care system recommendations:

- CCGs, STPs and Alliances to work with TCST to improve the information available to service users on how to access cancer rehabilitation services
- All CCGs, STPs, Alliances to identify a 'rehabilitation champion' to ensure rehabilitation is given 'parity of esteem' at top table conversations and is fully considered in all decision-making about the care of people living with and beyond cancer
- London CCGs, STPs and Alliances to focus on working toward achievement of national and local targets for Living with and Beyond Cancer metrics to contribute to addressing the personalised needs for people with cancer
- CCGs, STPs, Alliances to work with TCST to promote the role of AHPs in personalised care interventions (Holistic Needs Assessments, Treatment Summaries and Health and Wellbeing Events) and Stratified Care Pathways.
- CCGs and STPs to gather information on how cancer rehabilitation services are being commissioned.

Next Steps

The next steps for this work are to develop a detailed implementation plan and TCST resource will be needed to support implementation. The next steps include:

- TCST and Macmillan Cancer Support (including Macmillan GPs, Trust Recovery Package Managers, Communities of Practice and London Macmillan partnership managers) to raise awareness and profile of cancer rehabilitation in London.
- 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 (CCB) in Winter 2019.

- TCST & Macmillan Cancer Support to conduct a 6 month evaluation of London eHNA data on cancer rehabilitation and report findings back to LWBC Partnership Board and CCB (May– Dec 2019)
- TCST to continue to work with Arms Length Bodies (ALBs) and other partner organisations to explore opportunities for wider scale piloting of a minimum dataset (ongoing)
- TCST to refine the service improvement tools following a 6-month evaluation period (June – August 2019)
- TCST will continue discussions with Macmillan Cancer Support and partner organisations such as NHS England/Improvement to explore the potential for benchmarking cancer rehabilitation across services in London.

Acknowledgments

The Transforming Cancer Services Team (TCST) would like to thank Macmillan Cancer Support for funding Dr Karen Robb, Macmillan Rehabilitation Clinical Lead to carry out this project over the last three years.

A huge thanks to the Cancer Rehabilitation Steering Committee for their wisdom, expertise and patience, and for helping TCST to keep this work on track. We are hugely grateful to all the service users and carers who have given up their time to support this work, and who have ensured that the patient voice has been central to all discussions and decisions. To the many professionals who have advised on this work, and allowed TCST to promote this work at their events; we appreciate your support and enthusiasm.

And finally a massive thanks to the Personalised Care in Cancer team (previously the Living With and Beyond Cancer team) within the TCST, for their encouragement and guidance and eternal optimism.

About the author

Dr Karen Robb is the Macmillan Rehabilitation Clinical Lead for the Personalised Care for Cancer team within TCST. She is a chartered physiotherapist and a member of the Chartered Society of Physiotherapy Council. She has over 20 years' experience in cancer care and is a specialist in cancer rehabilitation. Karen is part of an international team reviewing cancer rehabilitation guidelines as part of the World Health Organisation Rehab 2030 initiative.

Why this work was undertaken

Cancer rehabilitation is an integral and essential component of high quality cancer care¹ and is a key theme in the Cancer Taskforce recommendations². Rehabilitation plays an important role in the care of people living with and beyond cancer, and it is likely that demand for services will grow as our population ages, and more people survive cancer and live with the consequences of their cancer treatment.

Despite the importance of cancer rehabilitation for people and populations, previous work by the author has shown that there are many challenges facing rehabilitation services in London including:

- Poor awareness of the scope and breadth of rehabilitation and the fact that it happens³ along and across every pathway of care
- Little to guide commissioners and others on what good looks like and how to measure it⁴
- Lack of quality data relating to many aspects of rehabilitation service delivery⁵.

The Personalised Care in Cancer Team of TCST has a remit to provide 'once for London' clinical and strategic guidance to commissioners and decision-makers in London. This is done through extensive stakeholder engagement and the co-creation of comprehensive guidance, models of care and business cases.

In August 2016, the Living with and Beyond Cancer team published '[Commissioning Guidance for Lymphoedema Services for Adults Living With And Beyond Cancer](#)'⁶, to address the inequalities in service provision across London, highlight areas for improvement and influence around the economic arguments for change. TCST also produced [a template business case for lymphoedema services](#) in June 2017⁷. The work has been impactful in a number of ways:

- It has been well received in London and has influenced the creation of new services (albeit at various stages of development)
- It has been published in a peer reviewed journal and presented at various national and international conferences

¹ NCAT (2013), *Cancer Rehabilitation: making excellent cancer care possible*
http://webarchive.nationalarchives.gov.uk/20130513211237/http://www.ncat.nhs.uk/sites/default/files/work-docs/Cancer_rehab-making_excellent_cancer_care_possible.2013.pdf

² NHS England (2016), *Achieving World-Class Cancer Outcomes: Taking the strategy forward*
<https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf>

³ NHS England (2016), *Improving Rehabilitation Services Programme Regional Report – London*
<https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2016/09/rehab-leads-report-london.pdf>

⁴ Ibid

⁵ Ibid

⁶ Healthy London Partnership (2017), *Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer*
<https://www.healthylondon.org/wp-content/uploads/2017/10/Commissioning-guidance-lymphoedema-August-2016.pdf>

⁷ Healthy London Partnership (2017), *Lymphoedema services for adults living with and beyond cancer: A template business case for commissioners*
<https://www.healthylondon.org/resource/template-business-case-lymphoedema-services/>

- It received a commendation in the Healthcare Transformation Awards 2018
- It has influenced and shaped [new national guidance by the National Lymphoedema Partnership](#)⁸, and
- It has led to the creation of a new Macmillan funded Community of Practice for professionals.

In May 2018, the TCST team produced [‘The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer’](#)⁹ to outline what psychosocial support was already being commissioned, set out the key components of a psychosocial care pathway, and provide recommendations for improving care. This work built on previous [commissioning guidance](#) published in 2015¹⁰. This work has been impactful in London and has resulted in:

- Significant engagement across London between commissioners, service providers (primary and secondary care), service users and the third sector with the shared goal of improving psychosocial support across the cancer pathway
- TCST providing bespoke support to STPs in London to address inequity of provision and reduce unwarranted variations in care.
- The commissioning of new psycho-oncology services within the largest STP in London
- Successful ‘triple integration’ between primary and secondary care, physical health and mental health and health and social care. in various areas of London
- Clear referral criteria being established across the pathway to ensure that patients will receive the most appropriate psychosocial support at the right time and in the right place.
- Clarity on the education, training, and supervision needs of all those working with adults affected by cancer across primary care, community services and the acute sector.
- The London Integrated Pathway for Cancer Psychosocial Support being presented both nationally and internationally
- TCST being consulted with both within London and outside of London to share knowledge and expertise regarding how to implement the pathway locally.

There has been significant learning for the TCST from both the work in lymphoedema, and psychosocial care. The impact from both work-streams has re-enforced the importance of developing and implementing ‘once for London’ Integrated Care System

⁸ National Lymphoedema Partnership (2019), *Commissioning Guidance for Lymphoedema Services for adults in the UK* https://www.lymphoedema.org/images/pdf/NLP_Commissioning_Guidance_March_2019.pdf

⁹ Healthy London Partnership (2018), *The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer* <https://www.healthylondon.org/wp-content/uploads/2018/05/Psychological-support-for-people-affected-by-cancer-May-2018.pdf>

¹⁰ London Strategic Clinical Networks (2015), *Psychological support for people living with cancer Commissioning guidance for cancer care in London* <http://www.londonscn.nhs.uk/publication/psychological-support-for-people-living-with-cancer/>

guidance to support the personalised care agenda. There is now a clear need for guidance to identify what good cancer rehabilitation looks like, and to support and improve the commissioning of services in London.

1. Background

1.1 Defining Cancer Rehabilitation

'Rehabilitation is a central element of cancer care and a key theme of the Cancer Taskforce recommendations. It enables patients to make the most of their lives by maximising the outcomes of their treatment and minimising the consequences of treatment and symptoms such as fatigue, breathlessness and lymphoedema. The need for rehabilitation starts at the point of diagnosis by helping patients prepare for treatment ('prehabilitation') and discharge home. It can help patients get well and stay well and addresses the practical problems caused by the disease and treatment, helps patients become as independent as possible and minimise the impact on carers and support services'

Macmillan Cancer Support

Rehabilitation has been defined by the World Health Organisation as, "a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments" and 'is instrumental in enabling people with limitations in functioning to remain in or return to their home or community, live independently, and participate in education, the labour market and civic life'¹¹.

However, many will argue that rehabilitation is more than just a set of measures; it is a partnership, a holistic way of working incorporating physical and psychosocial dimensions. It encompasses personalised care, supports self-management, is goal-orientated and is flexible, proactive and timely.

1.2 The impact of cancer and its treatment

In a 2013 report, Macmillan Cancer Support estimated that 25% of people living after cancer treatment in the UK face long-term effects of treatment¹². These can include a wide range of physical, psychological and social consequences of treatment, some of which might not arise for many months or years after treatment has taken place. This report also highlighted that many people receiving cancer treatment will also have shorter-term consequences of treatment, with many requiring emotional support and experiencing financial impact of a cancer diagnosis (See Figure 1).

Many individuals living with the consequences of treatment (whether they be short, medium or long-term) will require assessment and management by rehabilitation services. Some individuals will require specialist input where the rehabilitation professional fully understands the cancer, the implications for the individual and the

¹¹ World Health Organisation (2011) Guidelines on Health-Related Rehabilitation (Rehabilitation Guidelines). Available at: https://www.who.int/disabilities/care/rehabilitation_guidelines_concept.pdf

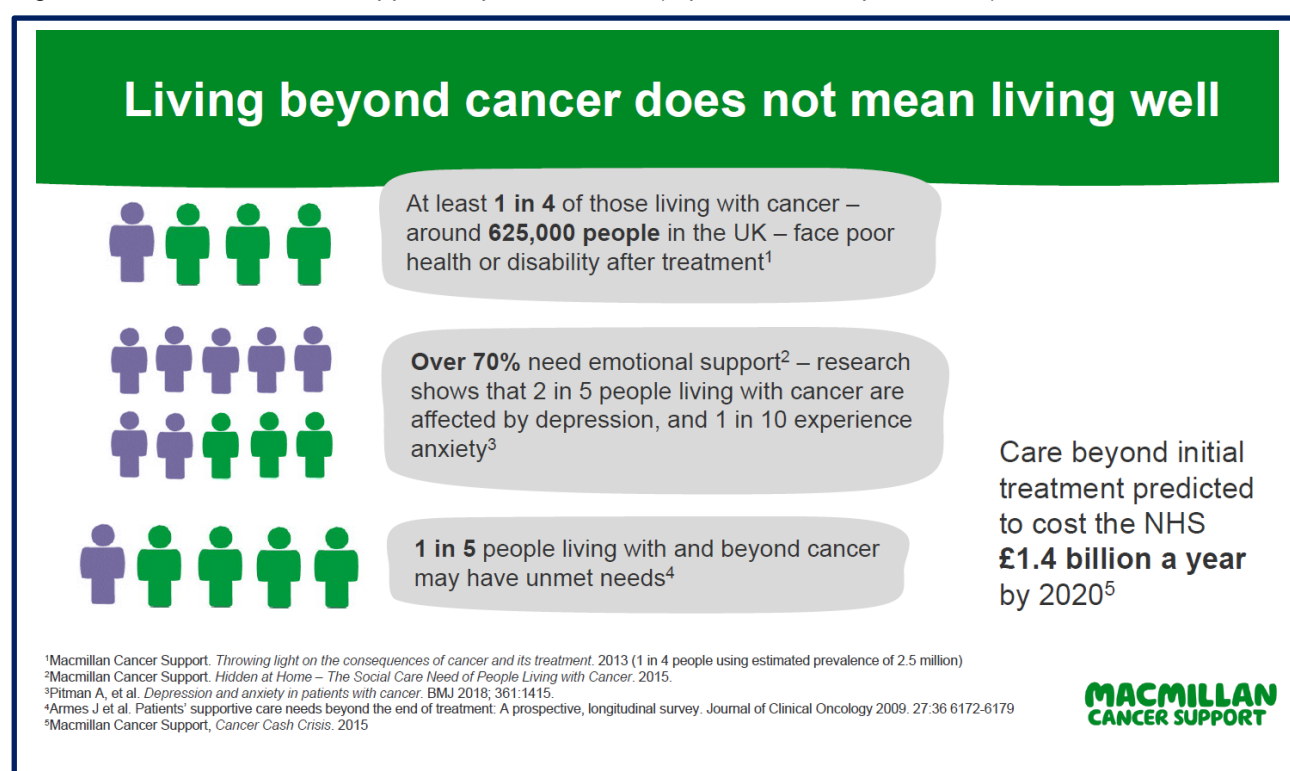
¹² Macmillan Cancer Support (2013), *Throwing light on the on the consequences of cancer and its treatment* <https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf>

evidence-based approaches to management. This is discussed in more detail in Section 1.3, see Fig 9.

Further 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 grow¹³. Figure 2 shows how the prevalence is expected to double by 2030, but also how the number of people in the early and late monitoring phase are expected to be the biggest group. These groups will be living with the consequences of treatment and likely to have rehabilitation needs.

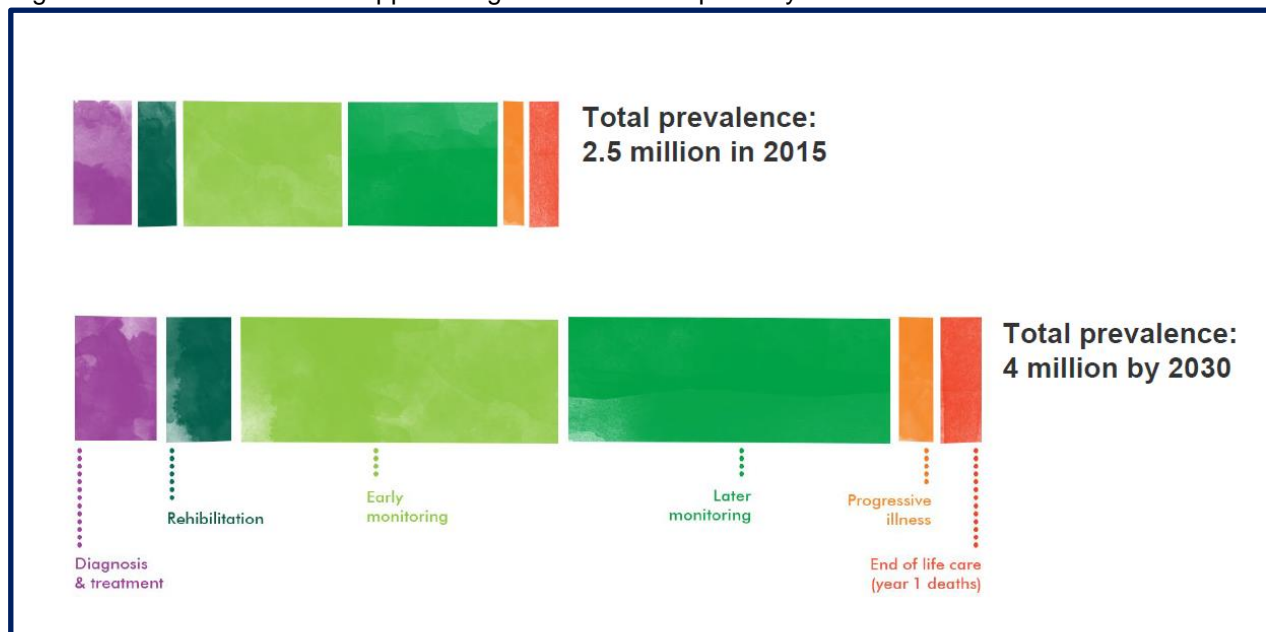
It is also predicted that the age profile of those living with or after a cancer diagnosis will change, with 73% of those living with or after a cancer diagnosis nationally to be aged over 65 by 2030, suggesting additional likelihood of co-morbidities and other complications. If these increased needs are not met, there are likely to be significant impacts on quality of life, as well as cost implications for the NHS with increased longer-term demand on services.

Figure 1: Macmillan Cancer Support: impact of cancer (reproduced with permission)¹⁴



¹³ Ibid

¹⁴ Jane Maher (2019) *Kings Fund: Living with and beyond cancer conference*. Reproduced with permission from Jane Maher, Joint Chief Medical Officer, Macmillan Cancer Support

Figure 2: Macmillan Cancer Support: stages of the cancer pathway¹⁵

The traditional medical model is not sufficient to fully meet the personalised care agenda, and a fundamental shift in thinking and behaviours will be needed to deliver better outcomes. The principles of personalised care involving a holistic, patient centred approach are inherent to the delivery of high quality rehabilitation, and there are many excellent examples of this approach in London (see Figures 3, 7, 8, 13, 14, 15, 18, 19, 22 and 24).

For example, the South East London Head and Neck Cancer Rehabilitation Team (CHANT) team provides a unique service dedicated to managing the consequences of head and neck cancer. The service is described below.

¹⁵ Derived from Yip K, McConnell H, Alonzi R, Maher J; *Using routinely collected data to stratify prostate cancer patients into phases of care in the UK: implications for resource allocation and cancer survivorship*, Br J Cancer; 2015;112: 1594–1602, doi:10.1038/bjc.2014.650

<https://www.ncbi.nlm.nih.gov/pubmed/25791873>

Maddams J, Utley M, Moller H. *Projections of cancer prevalence in the United Kingdom, 2010–2040*. Br J Cancer. 2012. 107: 1195–1202.

Figure 3: South East London Head and Neck Cancer Rehabilitation Team case study

The South East London Head and Neck Cancer Rehabilitation Team:**A one of a kind service providing personalised rehabilitation from acute to community care**

The South East London Head and Neck Cancer Rehabilitation team is the only comprehensive rehabilitation team of its kind in the UK, bringing specialist care closer to patients' homes. The team provides specialist intervention at every stage of the pathway, working across South East London to provide seamless care at Guy's Hospital, community clinics and at home.

The acute head and neck rehabilitation team provides multidisciplinary pre-treatment appointments for all patients, to assess their individual needs, set patient-led goals and prepare them for the effects of their treatment. All patients undergoing laryngectomy (removal of the voice box) are given the opportunity to meet a fellow patient to help prepare them and inform their consent. Dietitians provide carbohydrate loading advice pre-surgery to promote enhanced recovery.

'The aftercare I have received has been second to none – everything has been explained fully to me and I have improved immensely over the period since treatment. Thanks to your care I'm well on the road to recovery'

Patient

All patients who need it are given a prophylactic swallow exercise programme to help maintain swallow function during treatment, as well as specialist physiotherapy to manage the effects of treatment, focusing on airway, trismus, shoulder dysfunction and fatigue. The team also provides a SALT led surgical voice restoration service for those undergoing laryngectomy.

'The team listens and helps me work out what's best for me ... you can say how you feel and they help'

Patient

The community team (CHANT) comprises Specialist Speech and Language Therapists, Dietitians, Physiotherapists, Clinical Nurse Specialists and assistants. The team provides multidisciplinary joint rehabilitation appointments following treatment. They provide support for patients with tracheostomies to manage tubes at home, reducing hospital admissions

The CHANT team works with specialist services in the region, including palliative care, lymphoedema, psycho-oncology, dentistry, surgery and oncology, to provide holistic personalised care for patients who have life-changing treatment for head and neck cancer. The team is commissioned by and covers 6 CCGs, representing economies of scale in the provision of specialist cancer rehabilitation.

'The team focus on my experience and my concerns'

Patient

The team also works closely with the acute team to enable patients to move seamlessly between services, by information sharing, having regular meetings, as well as rotation and secondment opportunities in each part of the team to ensure all team members have a good understanding of the entire patient pathway

1.3 Understanding generalist rehabilitation and cancer rehabilitation: context, value and challenges for commissioning

Generalist Rehabilitation

Rehabilitation has been defined by the World Health Organisation as, "a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments" and 'is instrumental in enabling people with limitations in functioning to remain in or return to their home or community, live independently, and participate in education, the labour market and civic life'¹⁶.

There is global recognition that rehabilitation offers significant value to the wider health economy, and significant efforts are needed to improve the status quo. The World Health Organisation is leading an international effort entitled 'Rehabilitation 2030: a call for action'¹⁷ to strengthen rehabilitation services in member states, and tackle the many barriers to better care including insufficient rehabilitation workforce, and poor awareness. In an important editorial addressing the need for an international effort, the authors recognise the health and demographic trends of ageing populations, increasing prevalence of non-communicable diseases and the consequences of injuries and state:

*'The health, social and economic consequences of these trends should serve as a call to policy-makers to invest not only in health services that reduce mortality and morbidity, but also in those that improve functioning and consequently well-being. These latter outcomes are at the core of rehabilitation, yet rehabilitation services are often underdeveloped, under resourced and undervalued.'*¹⁸

In the UK, NHS England commissioning guidance for rehabilitation has highlighted the vital role that rehabilitation plays in delivering better outcomes for patients,

*'A modern healthcare system must do more than just stop people dying. It needs to equip them to live their lives, fulfil their maximum potential and optimise their contribution to family life, their community and society as a whole.'*¹⁹

This guidance outlines the extensive scope and breadth of rehabilitation, and the diversity and skills of rehabilitation workforce. Many will associate the delivery of rehabilitation with the Allied Health Professionals, however NHS England considers

¹⁶ World Health Organisation (2011), *Guidelines on Health-Related Rehabilitation (Rehabilitation Guidelines)*
https://www.who.int/disabilities/care/rehabilitation_guidelines_concept.pdf

¹⁷ World Health Organisation (2017) *A Call for Action: The need to scale up rehabilitation*,
<https://www.who.int/disabilities/care/NeedToScaleUpRehab.pdf>

¹⁸ Krug and Cieza (2017), *Strengthening health systems to provide rehabilitation services*, *Bull World Health Organ.* 2017 Mar 1;95(3):167. doi: 10.2471/BLT.17.191809

¹⁹ NHS England (2016) *Commissioning Guidance for Rehabilitation*
<https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf>

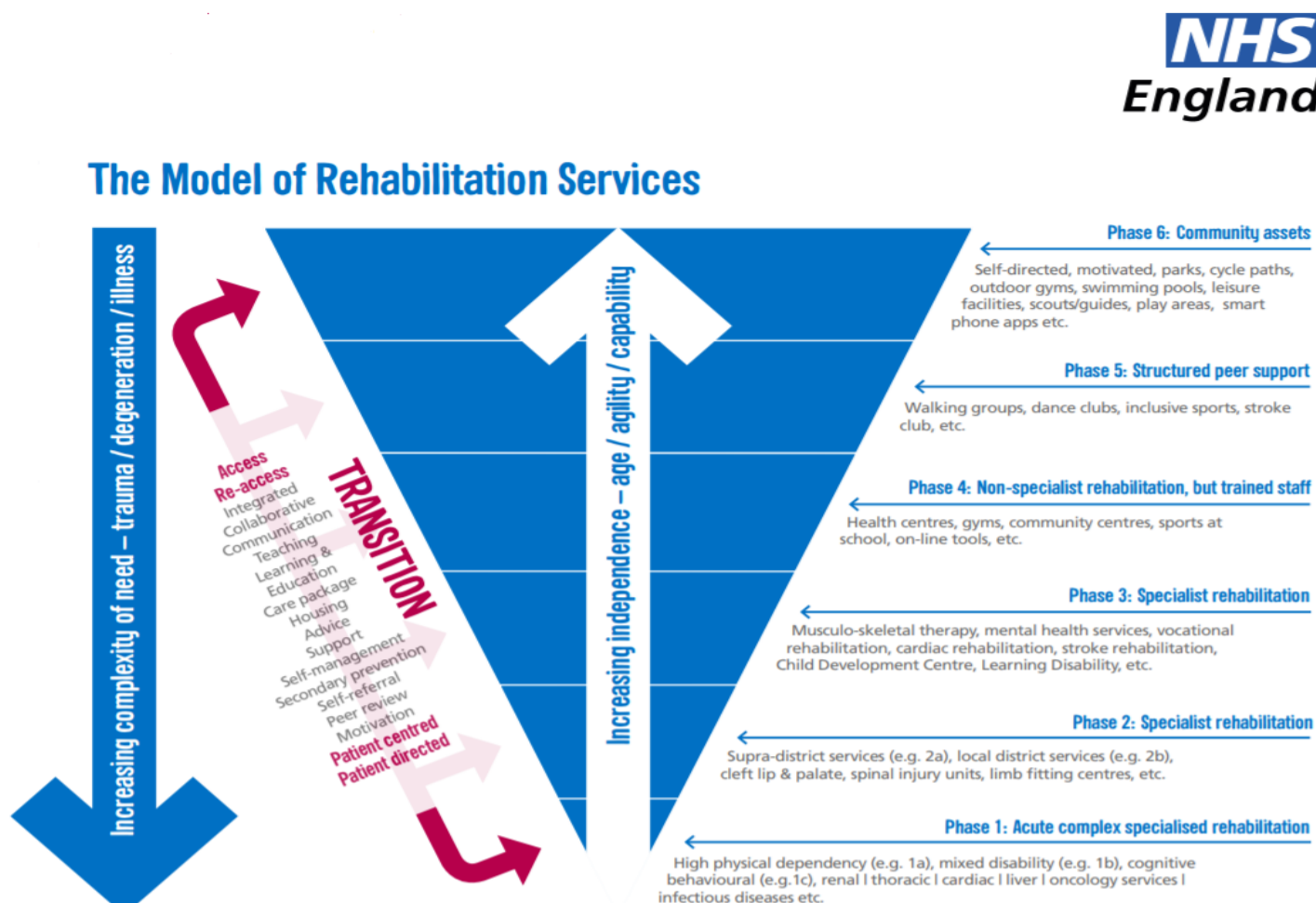
rehabilitation as being, ‘everyone’s business’ and ‘...is now central to the way we deliver our health services’²⁰.

‘It is increasingly acknowledged that effective rehabilitation delivers better outcomes and improved quality of life and has the potential to reduce health inequalities and make significant cost savings across the health and care system’

NHS England (2016)²¹

The Guidance includes “Principle and Expectations for good rehabilitation services”²² and acts as a blueprint for how services should be commissioned (see Fig 4). Some important ‘top tips’ for the commissioning of rehabilitation are shown in Fig 5.

Figure 4: NHS England, The Model of Rehabilitation Services



²⁰ Ibid

²¹ NHS England (2016), *Commissioning Guidance for Rehabilitation*

<https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf>

²² NHS Wessex Strategic Clinical Networks (2015), *Rehabilitation is everyone’s business: Principles and expectations for good adult rehabilitation*

<https://www.networks.nhs.uk/nhs-networks/clinical-commissioning-community/documents/principles-and-expectations>

Figure 5: NHS England, Ten top tips for commissioning local rehabilitation services



Ten top tips for commissioning local rehabilitation services

- 1. Recognise the rehabilitation you already commission:**
 - does your clinical commissioning group (CCG) have a listing of all providers and their rehabilitation services?
 - rehabilitation is essential in order to meet the requirements of domains 2 and 3 of the [NHS Outcomes Framework 2015/16](#)
 - do you know who commissions level 1 and 2 rehabilitation in your area (NHS England and surrounding CCGs)?
- 2. Have ambition for your services and the people they serve:**
 - consider encouraging services to start small and then support them to grow
- 3. Make your services “join up” and have some common key principles in your service specifications:**
 - does walking the pathway of care with a user identify any gaps or areas for improvement?
 - do you join up with other CCGs? Do you share risk for less common needs and presentations? For example, brain injury rehabilitation is often most effective for populations of 6-700,000
 - are there established communication channels between services, including between mental and physical health service providers?
- 4. Rehabilitation should not be “extra” or an “add-on” – it should be considered throughout each person’s journey:**
 - rehabilitation should be part of almost all pathway commissioning
 - have you considered how to meet both physical and mental health needs within rehabilitation services?
 - have you considered rehabilitation as integral to your sustainability and transformation plans?
- 5. Consider what outcomes you want; identify some common measures and ask your services to work together:**
 - establish what outcome measures are already being collected. Are they robust and can they be used for benchmarking?
 - what processes are in place to collect information on patient experience? How is this used by providers to improve service provision?
- 6. Consider the range of settings where your services are delivered, especially community settings, the third sector and care homes (including respite care):**
 - have you commissioned services that focus on care closer to home?
 - do your service specifications cover rehabilitation in care homes? This is particularly important for prevention of admissions and maintenance of long-term conditions? What are the governance arrangements?
- 7. Take a strategic view so that you invest to save.**
 - Have you considered how rehabilitation can help you deliver primary and secondary prevention and early intervention for your local diverse population?
 - Have you completed a joint strategic needs assessment for rehabilitation services identifying current inequalities in access and outcomes and future potential demand?
 - which services will deliver this across a life course and for particular care groups and types of condition?
 - would commissioning self-referral reduce pressure and costs in primary care services?
- 8. Cross- check your local services against the rehabilitation model to identify gaps or duplication and outcomes being achieved.**
- 9. Ask for advice and support if necessary:**
 - what forums do you use to share good practice locally, regionally and nationally?
- 10. Ask your providers and service users how improvements could be made and what can be done differently to improve outcomes for people:**
 - do you ensure dialogue for improvement and innovation between your providers and service users?

Cancer rehabilitation

Cancer rehabilitation is an essential component of high quality cancer care²³ and is a key theme in the Cancer Taskforce recommendations²⁴. Rehabilitation plays an important role in the care of people living with and beyond cancer, and it is likely that demand for services will grow as our population ages, and more people survive cancer and live with the consequences of their cancer treatment.

Economic benefits

AHPs are integral to the delivery of rehabilitation services and a comprehensive report of how AHPs improve cancer care, and save the NHS money stated, “there are clinical and

²³ NCAT (2013), *Cancer Rehabilitation: making excellent cancer care possible*

http://webarchive.nationalarchives.gov.uk/20130513211237/http://www.ncat.nhs.uk/sites/default/files/work-docs/Cancer_rehab-making_excellent_cancer_care_possible.2013.pdf

²⁴ NHS England (2016), *Achieving World-Class Cancer Outcomes: Taking the strategy forward*

<https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf>

financial risks in patients not receiving AHP input'²⁵. This 2012 document provides a comprehensive overview of the AHP contribution to the cancer pathway, with a focus on how AHPs support the Quality, Innovation, Productivity and Prevention (QIPP) agenda. The economic benefits of AHP contributions are illustrated through a range of 'golden nuggets' throughout the document, including:

- "It has been shown that if just half of breast cancer survivors who initially return to work but then leave were helped to stay in work the economy could save £30million every year"²⁶
- Dietetic advice and review of oral nutritional supplements results in more appropriate prescribing practices, the prevention and treatment of malnutrition, including reducing hospital admissions, improving patient outcomes and reducing GP visits'²⁷

A more recent report by the Nuffield Trust has highlighted the significant benefits of a prehabilitation programme for lung cancer patients at the Heart of England Foundation Trust. A feasibility study compared a multidisciplinary prehabilitation intervention with standard care; the prehabilitation programme resulted in lower post-op pulmonary complications (9% vs 16%), fewer re-admissions (5% vs 14%), and a total cost saving of £244 per patient, when compared to standard treatment²⁸.

An innovative therapy led rehabilitation service at Barts Hospital NHS trust (see Figure 18) has been funded by Macmillan Cancer Support with the aim of reducing length of stay and improving quality of life for neuro-oncology patients. Outcomes so far have been impressive with a preliminary report showing functional outcomes and patient experience are better, and cost-savings of up to £20k/month due to reducing length of stay. A case study in the report discusses a patient with a new diagnosis of lung cancer and metastatic spinal cord compression. It outlines that by improving his function and reducing his dependency, the service is saving more than £25,500 a year in community care costs.²⁹

Personalised Care agenda

Rehabilitation is a vital ingredient to ensure delivery of high quality personalised care across whole cancer pathways. For example,

1. Many of the symptoms identified in the electronic Holistic Needs Assessment (eHNA) may require onwards referral to AHPs e.g. fatigue, communication difficulties.

²⁵ NHS Networks (2012), *AHP Cancer toolkit*

https://www.networks.nhs.uk/nhs-networks/ahp-networks/ahp-qipp-toolkits/AHP_Cancer_Pathway_final%20-3.pdf/view

²⁶ Macmillan Cancer Support (2010), *Making it work: how supporting people to work after cancer is good for business, good for the economy, good for people with cancer*

<https://www.macmillan.org.uk/documents/getinvolved/campaigns/workingthroughcancer/makingitworkpolicy.pdf>

²⁷ London Procurement Programme (2010), *Review of Oral Nutrition Supplements*

²⁸ <https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-study-looking-at-rehabilitation-programme-for-people-having-lung-cancer-surgery>

²⁹ Chartered Society of Physiotherapists (2018), *Neuro-oncology: Cancer rehab really matters*
<https://www.csp.org.uk/frontline/article/neuro-oncology-cancer-rehab-really-matters>

2. Health and well-being events are an ideal opportunity to discuss key aspects of rehabilitation such as physical activity and dietary advice, and AHPs can play a key role.
3. Primary care led follow up must incorporate identification of consequences which are amenable to rehabilitation interventions such as urinary incontinence following surgery, or loss of muscle strength following hormone therapies.
4. Cancer Care Reviews must incorporate screening for long-term and late effects of cancer treatment, and ensure appropriate signposting and onward referrals are made efficiently and appropriately

Stages of cancer rehabilitation

Many people misinterpret cancer rehabilitation as something that happens after cancer treatment is finished, and is only required by a selection of individuals. However, there are four recognised stages of cancer rehabilitation, which illustrate how rehabilitation spans the entire treatment pathway contributing to a range of positive outcomes. These are described below, and again in Fig 6:

- Preventative: reducing impact of expected disabilities and improving coping strategies
- Restorative: returning an individual to previous levels of function
- Supportive: in the presence of persistent disease and need for treatment, rehabilitation is aimed at limiting functional loss and providing support
- Palliative: prevents further loss of function, measures are put in place to eliminate or reduce complications and to provide symptom management³⁰.

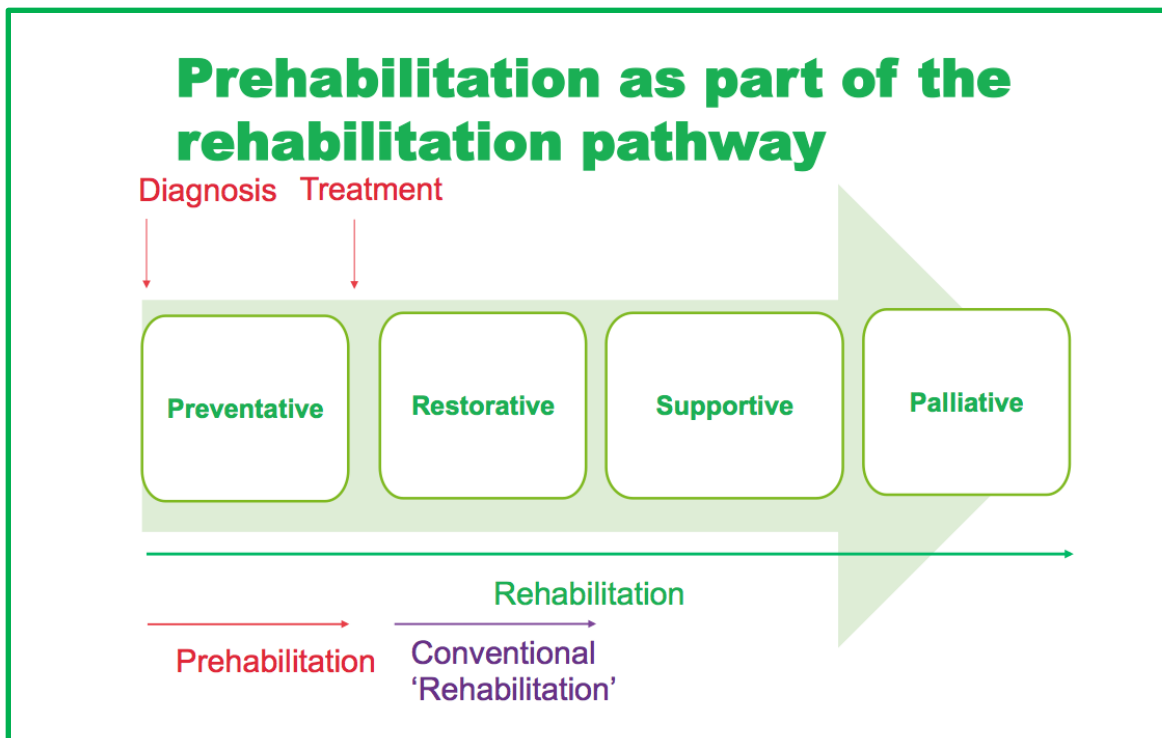
There is a growing interest in prehabilitation which has been defined, as “Preparation around the time of cancer diagnosis, before the beginning of treatment that includes lifestyle interventions that promote physical and psychosocial health to prepare for treatment and future impairments”³¹ and Macmillan Cancer Support has recently published detailed guidance for prehabilitation to support evidence-based practice and development of services in the UK³².

³⁰ Dietz, J.H (1980), *Adaptive rehabilitation in cancer*, Postgraduate Medicine, 68 (1): 145-153

³¹ Macmillan Cancer Support (2019), *The Fact Project*. (Courtesy of June Davis)

³² Macmillan Cancer Support (2019), *Prehab for People with Cancer: Principles and guidance for prehabilitation within the management and support of people with cancer*. <https://ebpom.org/download.php?fn=prehabilitation-guidance-for-people-with-cancer.pdf&mime=application/pdf&pureFn=prehabilitation-guidance-for-people-with-cancer.pdf>

Figure 6: Prehabilitation as part of the rehabilitation pathway, FACT Project, Macmillan Cancer Support, the Royal College of Anaesthetists and NIHR Nutrition and Cancer Collaborative (reproduced with permission).



The 'Get Set 4 Surgery service' at St George's NHS Foundation Trust provides a unique cancer prehabilitation service dedicated to improving physical and mental health outcomes from surgery. The service is described in Figure 7.

Figure 7: Get Set 4 Surgery Prehabilitation programme at St George's NHS Foundation Trust case study

Ready, Set, Go ... 'Get Set 4 Surgery' at St George's NHS Foundation Trust:

A cancer diagnosis and the prospect of surgery can leave people feeling anxious and disempowered. The 'Get Set 4 Surgery' multidisciplinary prehabilitation session provides support and education to patients, their family and friends, adopting a holistic approach to help patients be active in their own preparation and recovery.

The Get Set 4 Surgery initiative is delivered as one face-to-face multidisciplinary session. It is open to family and friends, supporting them to enable positive lifestyle changes at home. Patients hear advice on how to prepare mentally and physically for surgery from a range of professional groups including:

- Surgeons
- Anaesthetists
- Dieticians
- Psychologists
- Physiotherapists
- Nurse specialists
- Macmillan Cancer Support


"The whole experience was helpful, supportive and affirming. Every speaker was passionate about making the patient part of the team and that s/he has a responsibility within the care plan"

Patient

The team links simple lifestyle changes to improved fitness for surgery and a modified diet, and provides support on self-management and mental preparation for surgery. They discuss expectations and

strategies for improved recovery after surgery and signpost to other local groups which can provide support.

Patients also have time to tour the hospital, talk to health professionals and each other, and ask questions informally over coffee about their surgery. The service is supported by videos, booklets and a diary which helps patients set goals and record their progress in preparation for, and recovery from, surgery.



"Great that the session was open to patients' relatives/friends as well. Information and support is not just offered to the patient but to relatives and we were given lots of chances to ask questions and speak to Nurses/Doctors"

Patient

The service is responsive to patient feedback and now prioritises time for informal discussion with staff. Patient and family feedback is overwhelmingly positive; 100% of those who completed the Friends and Family Test recommended the service and said that they had all their questions answered.

Formal evaluation shows that after the session patients are inspired to improve activity levels and modify their diet; 97% of major surgery patients attending the sessions are mobile the first day after surgery, compared to 84% of those who do not.

In the past, palliative rehabilitation has been considered an oxymoron. [The Hospice UK report, Rehabilitative palliative care: enabling people to live fully until they die – A challenge for the 21st century](#)³³, illustrates the important role of rehabilitation for patients with a palliative diagnosis. The Therapy Team at Marie Curie Hospice Hampstead, provide personalised palliative rehabilitation with significant benefits their patients, as described below.

³³ Hospice UK (2015), *Rehabilitative palliative care: enabling people to live fully until they die – A challenge for the 21st century*. <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/rehabilitative-palliative-care/resources-for-rehabilitative-palliative-care>

Figure 8: Marie Curie Hospice Hampstead case study

What matters to you?: Marie Curie Hospice Hampstead Therapy Team

"What matters to me is that you've taken the time to talk to me"

Patient

The Marie Curie Hospice Hampstead Therapy Team is a specialist oncology and palliative care team providing personalised inpatient and outpatient rehabilitation to patients across Marie Curie Hospice Hampstead and the Royal Free Hospital.

The Therapy Team is made up of physiotherapists, occupational therapists, dieticians and therapy assistants. They work closely with the multidisciplinary teams at the Marie Curie Hospice Hampstead to provide integrated and personalised rehabilitation. The team tailor care to their patients' needs and goals, providing many interventions as needed. These include 4 gym-based sessions every week, hydrotherapy and individual sessions for breathlessness and fatigue management.

Integral to the team's approach to personalised care is to ask each of their inpatients, every week 'what matters to you?' to facilitate meaningful conversations around what was important to them. This enables conversations around how they would like to be supported with their current priorities and goals. This approach was embedded as a core part of the MDT meetings; each patient is now introduced by their name, age and importantly, by describing what matters most to them before their medical diagnosis and symptoms are discussed. Prior to this approach, the team members tended to focus on questions specific to their speciality (for example, physiotherapists asking about mobility and doctors asking about pain or medication). Now questions are centred around the care of the whole person and team meetings are more patient focused, with a greater understanding of what matters to patients, their interests and needs.

"No-body has ever asked me these types of questions before"

Patient

Patients have valued this approach to personalised care and its impact on their quality of life. Over 70% patients reported that therapy at the hospice very much impacted on their overall health, wellbeing and quality of life. The MDT have also reported that it has helped them focus on patients' priorities and that these conversations are helping them learn more about how to best deliver care in a meaningful way.

Assessment of cancer rehabilitation needs

People living with and beyond cancer should have their rehabilitation needs assessed at all key stages of the pathway, and be signposted to the appropriate professionals as required, including health, social care, leisure industry etc. Although there is no standardised generic cancer rehabilitation assessment tool available, a range of resources are available to help this process including the [HNA³⁴](#), [Cancer Rehabilitation](#)

³⁴ Macmillan Cancer Support (2019) *Recovery Package resources: Holistic Needs Assessment*. <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774>

[Pathways](#)³⁵ and [AHP prompt tool](#)³⁶. Tumour and symptom specific tools are available but discussion of these is beyond the scope of this guidance.

Cancer rehabilitation workforce

Cancer rehabilitation is provided by a workforce that includes both ‘specialists’ and ‘generalists’. Previous NICE Guidance outlined 4 levels of care as shown in Figure 9³⁷.

Figure 9: NICE recommended model of rehabilitation assessment and support

Recommended model of rehabilitation assessment and support				
Level	Patient need (examples)	Group providing input	Assessment	Intervention
1	<ul style="list-style-type: none"> Simple energy conservation techniques Simple or first-line dietary advice Advice to patients regarding skin care and risks of developing lymphoedema 	<ul style="list-style-type: none"> Patients and carers' assessment General nursing staff Therapy radiographers Assistant practitioners/support workers 	Recognition of needs for help and support based on assessment of function	Basic interventions, including self-management, and care strategies initiated by generalist health care professionals
2	<ul style="list-style-type: none"> Post-operative physiotherapy following breast surgery Dietary advice for patients having enteral feeding regime 	Generalist AHPs	Routine assessment of rehabilitation needs	Interventions provided for commonly presenting rehabilitation needs - post-operative input plus management of commonly presenting side-effects of treatment or functional impairment
3	<ul style="list-style-type: none"> Post-operative physiotherapy following breast surgery Dietary advice for patients having enteral feeding regime 	Experienced AHPs with basic level training in cancer rehabilitation working at senior level	Specialist assessment from an experienced AHP	Interventions provided by professionals with knowledge and experience of effects of cancer treatment and aetiology; interventions requiring knowledge of the impact of disease
4	<ul style="list-style-type: none"> Management of a patient with spinal cord compression Swallowing assessment for patient having had radical head and neck surgery Management of severe/complicated lymphoedema 	Advanced practitioner AHPs working predominantly or exclusively with patients with cancer and with higher-level training as specialist practitioners	Highly specialist assessment from expert AHP	Highly specialist interventions for patients having radical surgery, patients with advanced disease, patients with severe functional impairment, patients undergoing combination therapies and/or patients with complex end of life issues

³⁵ Macmillan Cancer Support (2019) Practical resources for healthcare professionals: Cancer Rehabilitation Pathways <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package/resources.html#297774>

³⁶ London Cancer Alliance (2017) Cancer Rehabilitation: An Overview and Prompt Tool. <http://rmpartners.cancervanguard.nhs.uk/wp-content/uploads/2017/03/lca-rehabilitation-referral-prompt-tool-december-2015.pdf>

³⁷ NICE (2004), *Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer* <https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005>

As shown in Figure 9, not all cancer patients with rehabilitation needs require management by a cancer rehabilitation specialist (NICE levels 3 & 4) and many will have their rehabilitation needs adequately met by non-cancer rehabilitation services. For example, a woman requiring post-operative physiotherapy for a stiff shoulder following breast surgery can be referred to out-patient musculoskeletal services for assessment and treatment. However, if the woman experiences a range of additional consequences of treatment such as lymphoedema and fear of recurrence, she will require assessment and management by a physiotherapist with highly specialised skills.

Macmillan Cancer Support have produced an [AHP competency framework](#)³⁸ to support the workforce working with people affected by cancer. The framework acknowledges that, 'AHPs need to have a detailed knowledge of cancer, the treatments and the care pathways available. They need to know who the other members of the multidisciplinary team are and how they can help. They need a sound knowledge of the best practice available'. The framework describes 3 levels of competencies; competent, specialist and highly specialised.

[The Cancer Strategy for England](#)³⁹ identified that many patients 'do not have sufficiently early access to AHP support' and there is a growing need to improve recruitment and retention of specialists, as well as develop the skills of the generalist cancer rehabilitation workforce⁴⁰. Early access to cancer rehabilitation is crucial in preventing the development of chronicity.

Robb and Davis (2016)⁴¹ summarised the challenges in delivering high quality cancer rehabilitation when exploring whether cancer rehabilitation has achieved parity of esteem in our current healthcare environments:

'Moving forward, it appears there are many challenges facing the cancer rehabilitation community and in the authors' opinion, little will change without a fundamental shift in the values of the health and social care system. We need to move towards a biopsychosocial model of care utilising holistic approaches with a focus on enablement and putting patients goals at the heart of care delivery. We need an empowered rehabilitation workforce with the skills and evidence-base to facilitate transformational change. And finally we need the support of the whole community to pull together with one common goal; to improve rehabilitation services for all patients who require it, wherever and whenever that may be. Only then will cancer rehabilitation achieve parity of esteem'.

³⁸ Macmillan Cancer Support (2017), *The Macmillan Allied Health Professionals Framework: for those working with people affected by cancer* https://www.macmillan.org.uk/_images/allied-health-professions-framework_tcm9-314735.pdf

³⁹ Independent Cancer Taskforce (2015), *Achieving World-Class Outcomes A Strategy for England 2015-2020* https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

⁴⁰ Macmillan Cancer Support (2017), *Thinking differently: Macmillan's vision for the future cancer workforce in England* https://www.macmillan.org.uk/_images/thinking-differently-cancer-workforce-report_tcm9-309910.pdf

⁴¹ Robb and Davis (2015), *Examining progress in cancer rehabilitation: are we closer to parity of esteem?* *European Journal of Cancer Care*, 2015, 24, 601–604 <https://onlinelibrary.wiley.com/doi/pdf/10.1111/ecc.12369>

1.4 National context

The changing cancer story

Cancer is a national priority for NHS England and there is increasing awareness of the need to improve the care of people living with and beyond cancer⁴². Half of people born since 1960 will be diagnosed with cancer in their lifetime and more than half of people receiving a cancer diagnosis will live ten years or more⁴³. An ageing population, combined with increased survival rates, means that the number of people diagnosed and living with cancer will continue to grow rapidly, even with improvements in prevention. There are currently approximately 2.5 million people living with cancer in the UK, and this is projected to increase to 5.3 million by 2040⁴⁴.

25% of people with cancer face poor health or disability after treatment, 70% are also living with at least one other long-term condition and nationally it is estimated that 700,000 people are living with cancer and three or more long-term conditions⁴⁵. There is a recognition that for many people, cancer should be viewed as a long-term condition⁴⁶, a vision which was developed by the Transforming Cancer Services Team for London (TCST) and endorsed by the London Cancer Commissioning Board in December 2015, and again in July 2018. It is clear that as the cancer story is changing we need to radically rethink how we are delivering care for our populations.

Levers and Drivers

The NHS England Long-Term Plan (LTP) was published in January 2019 and provides a blueprint for the future of the NHS. The LTP sets out how the NHS will move towards new service models; strengthen its contribution to prevention and health inequalities; improve quality of care and outcomes; tackle workforce challenges; upgrade technology and digital solutions, and deliver a sustainable financial future. There are continued commitments to improving cancer survival and early diagnosis, and further emphasis on every cancer patient having a care plan and opportunity to access stratified follow-up. In addition, the LTP has identified a range of priority areas, which are vital to consider when planning care for people living with and beyond cancer. These include:

- An all age, whole population approach to personalised care (See Figure 10)
- A focus on helping people age well
- Preventing emergency admissions and speeding up discharge

⁴² Independent Cancer Taskforce (2015), *Achieving World-Class Outcomes A Strategy for England 2015-2020*

https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

⁴³ Macmillan Cancer Support (2015), *The burden of cancer and other long-term conditions*

<https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf>

⁴⁴ Macmillan Cancer Support (2019), *Cancer Statistics: people living with cancer* <https://www.macmillan.org.uk/about-us/what-we-do/evidence/cancer-statistics.html#260408>

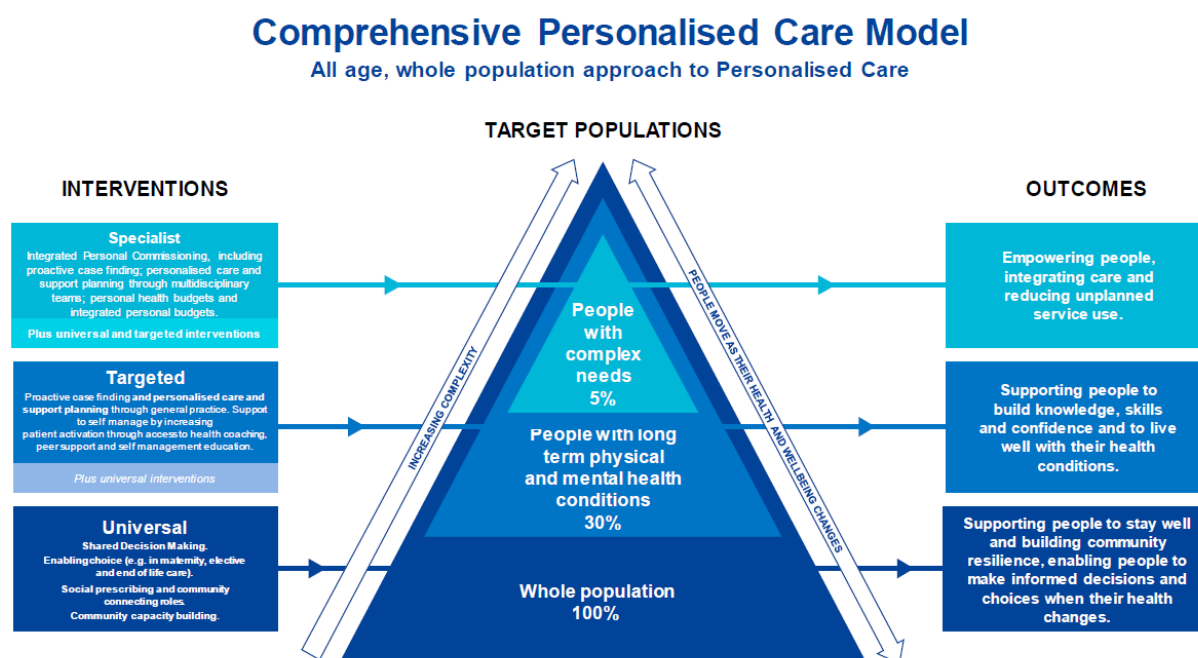
⁴⁵ Macmillan Cancer Support (2015), *1.8 million people are living with cancer and another long term condition*

https://www.macmillan.org.uk/aboutus/news/latest_news/18millionpeoplearelivingwithcancerandanotherlongtermcondition.a.spx

⁴⁶ TCST (2018), *Commissioning and delivery toolkit for cancer as a long-term condition*

<https://www.healthylondon.org/resource/commissioning-and-delivery-toolkit-for-cancer-as-a-long-term-condition>

- Investment and transformation in primary and community care services
- Developing social prescribing and Personal Health Budgets
- Developing the workforce: creating opportunities through leadership and working at top of scope of practice.

Figure 10: NHS England Comprehensive Personalised Care Model⁴⁷

The LTP sets out an ambitious vision for a move towards the establishment of integrated care systems across the entire country by April 2021. Primary care will be at the heart of integrated care systems and is key to delivering the ambitious transformation agenda. The primary care landscape is currently going through a major shift towards new models of at scale working centred around primary care networks, which will be at the foundation of new service models. The primary care transformation agenda is enabled by new funding flows and the vision as set in the GP Forward View⁴⁸ the Long Term Plan, the new GP contract⁴⁹ and, for London, the 'Next steps commissioning framework'⁵⁰ - a vision for strengthening general practice'.

Primary care networks will be the key delivery vehicle for increased out of hospital care and provision of more personalised, digitally enabled, population-focused care. They will consist of groups of general practices working together with a range of local providers, including across primary care, community services, social care and the voluntary sector, to offer more personalised, coordinated health and social care to their local populations.

⁴⁷ NHS England (2019), *Comprehensive Personalised Care Model*

<https://www.england.nhs.uk/wp-content/uploads/2019/02/comprehensive-model-of-personalised-care.pdf>

⁴⁸ NHS England (2016), *General Practice Forward View*

<https://www.england.nhs.uk/wp-content/uploads/2016/04/gpfv.pdf>

⁴⁹ NHS England (2019), *A five-year framework for GP contract reform to implement The NHS Long Term Plan*

<https://www.england.nhs.uk/gp/gpfv/investment/gp-contract/>

⁵⁰ Healthy London Partnership (2018), *Next steps to the Strategic Commissioning Framework: A vision for strengthening general practice collaboration across London*

<https://www.healthylondon.org/wp-content/uploads/2018/10/HLP-Next-Steps-Commissioning-Framework-2018.pdf>

Networks will be based around natural local communities typically serving populations of 30,000 to 50,000.

Primary care networks will operate in partnership with other agencies, both health and non-health, statutory and voluntary, to help deliver a wide range of national and local commitments. Care will be delivered by enhanced community multi-disciplinary teams working together that deliver an expanded and enhanced range of services closer to home. Expanded neighbourhood teams will comprise a range of staff such as GPs, pharmacists, district nurses, community geriatricians, dementia workers and AHPs (such as physiotherapists and podiatrists), joined by social care and the voluntary sector. This changing landscape provides significant opportunities for the development of cancer rehabilitation services including:

- Establishing rehabilitation as an essential component of personalised care
- Developing rehabilitation within the work-plan of the integrated care systems, and as a priority area for STPs
- Developing rehabilitation services within primary care networks, and facilitating the shift from acute to community based models
- Developing rehabilitation services which align with other priority areas such as social prescribing
- Developing digital enhancements to rehabilitation services
- Developing leadership roles to champion rehabilitation and ensure that rehabilitation is considered at all 'top table' discussions

The NHS England Cancer Transformation Funding enables Cancer Alliances across England to develop improvement projects across many aspects of personalised care for people living with and beyond cancer.

Work is underway within the National Cancer programme to develop a 'Quality of Life' metric which will allow this vital component of patient experience to be routinely recorded in the national database and used to inform care delivery. The final tool is expected for rollout in 2019/20.

The important role of AHPs in cancer has been recognised by NHS England and a recent publication⁵¹ highlights how AHPs support the strategic aims of the NHS in transforming care and improving quality of life. This online publication supports the drive to improve outcomes and reduce inequalities, and includes a selection of exemplar AHP services. The Chief Allied Health Professional's Office also recently launched their Digital Framework for AHPs⁵² to support a move towards digital solutions that are fully integrated with services and systems. A recent publication by NHS Improvement

⁵¹ NHS England (2018) *Quick Guide: the role of allied health professionals in supporting people to live well with and beyond cancer* <https://www.england.nhs.uk/wp-content/uploads/2018/10/quick-guide-ahp-cancer.pdf>

⁵² NHS England (2019), *A Digital Framework for Allied Health Professionals* <https://www.england.nhs.uk/publication/a-digital-framework-for-allied-health-professionals/>

supports a drive to improve the presence and development of AHP leadership in trusts⁵³. All of these initiatives support the AHPs into Action framework⁵⁴.

There is significant opportunity to align developments in cancer rehabilitation with work in other NHS national programmes. For example:

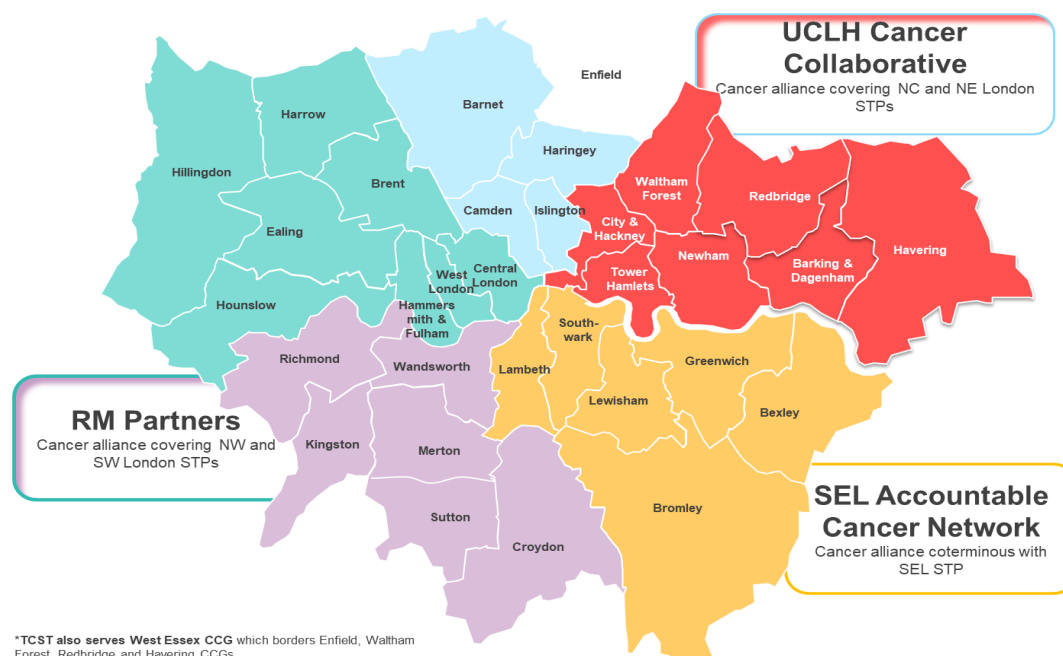
- The NHS England/Improvement Right Care Community Rehabilitation Toolkit is being developed with a wide range of stakeholders, with the key aim of providing a framework that local health economies can use to identify their opportunities and priorities in commissioning community rehabilitation care for their local population. The toolkit identifies key areas of focus, provides targeted actions that local systems can implement and provides an opportunity to self-assess and benchmark current systems to find opportunities for improvement.
- The NHS England/Improvement Model Hospital programme has a workstream dedicated to AHP workforce productivity.

1.5 London context

Overview and strategic priorities

The commissioning landscape in London and West Essex is complex and includes 5 STPs, 33 CCGs, three Cancer Alliances and one TCST (see Fig 11).

Figure 11: London's cancer system(s)



4

⁵³ NHS Improvement (2018), *Leadership of allied health professions in trusts: what exists and what matters An evaluation summary and self-assessment for trust boards*

https://improvement.nhs.uk/documents/2904/Leadership_of_AHPs_in_trusts.pdf

⁵⁴ NHS England (2017) *Allied Health Professions into Action: Using Allied Health Professionals to transform health, care and wellbeing, 2016/17 - 2020/21*

<https://www.england.nhs.uk/wp-content/uploads/2017/01/ahp-action-transform-hlth.pdf>

The London region will be working to meet the national priorities as laid out in the Long Term Plan. This includes addressing improvement of cancer services as a continuing national clinical priority, alongside regional clinical priorities such as respiratory, children and young people, frailty and mental health.

The NHS Long Term Plan highlights a greater need for prevention and population enablement, including closer consideration of social determinants of health. Londoners will be supported to make best use of community assets, supported through social prescribing as part of the primary care toolkit. Services users will have greater access to multidisciplinary teams in primary care and community settings, providing services in the most appropriate and accessible setting. This includes the formation of new primary care networks and integrated care systems – enabling greater collaboration between organisations and sectors.

Digitally enabled care will form part of routine practice for better communication, sharing skills, creating evidence and giving patients more choice about how they access services. Frontline staff and service users will need to work together to develop digital innovations that work for citizens.

Alongside these systems developments, workforce needs are a key feature of the Long Term Plan and regional priorities; ensuring we have a multidisciplinary workforce with capacity and capability fit for the future. This includes developing new skills, creating sustainable supply of new entrants into the qualified and support workforce and ensuring training routes are support diversification of the workforce.

Cancer prevalence

In London and West Essex, there are expected to be around 387,000 people living with and beyond cancer by 2030⁵⁵. Figure 12 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 London and in West Essex CCG. This data gives an indication of the likely number of people living with common long-term effects per STP, highlighting the need for well-resourced and integrated rehabilitation services.

⁵⁵ Maddams J, Utley M, Møller H (2012), *Projections of cancer prevalence in the United Kingdom, 2010-2040*. Br J Cancer; 107: 1195-1202

Figure 12: People in London Living With and Beyond Cancer in 2017⁵⁶

STP	Number of people living with or after cancer diagnosis in 2017	Predicted number of people living with long-term consequences of treatment ⁵⁷
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
West Essex CCG	11,453	2,863

Analysis of Electronic Holistic Needs Assessment Data

The London electronic Holistic Needs Assessment (e-HNA) tool data provides detail of the common concerns reported by people living with and beyond cancer, and importantly, many of these are amenable to rehabilitation intervention⁵⁸. Analysis of the 2017 data illustrates (in order) the top ten most common concerns reported by patients participating in the tool as:

1. Worry fear or anxiety
2. Tired, exhausted or fatigued
3. Pain or discomfort
4. Eating, appetite or taste
5. Sleep problems
6. Moving around (walking)
7. Work or education
8. Sadness or depression
9. Money or housing
10. Difficulty making plans

Whilst this data is limited in terms of the number of London trusts using the e-HNA tool (and therefore the number of patients participating), this analysis provides insight into

⁵⁶ TCST, NHS National Cancer Registry and Analysis Service (NCRAS), Public Health England and Macmillan Cancer support (2019), *2017 Cancer Prevalence Dashboard*
<https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

⁵⁷ Based on figures estimated by Macmillan Cancer Support: 25% of people living after cancer treatment in the UK face long-term effects of treatment. Macmillan Cancer Support (2013), *Throwing light on the on the consequences of cancer and its treatment*
<https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf>

⁵⁸ Macmillan Cancer Support (2018), *Cancer Rehabilitation Pathways*
<https://www.macmillan.org.uk/assets/macmillan-cancer-rehabilitation-pathways.pdf>

the primary concerns and support needs patients report both before and following treatment.

Furthermore, analysis shows that the rates at which these issues are reported varies by cancer type, as well as at different points in the pathway. For example, tiredness, exhaustion or fatigue was the second most frequently reported concern across all patients participating in the e-HNA in London. 34% of lung cancer patients highlighted this as a concern, as well as 27% of patients with haematological cancers and 22% of breast cancer patients. This issue was also the third most frequently reported concern for those with gynaecological, lower GI and lung cancers and sarcoma. Cancer rehabilitation has an important role in managing fatigue⁵⁹.

Cancer rehabilitation also provides a crucial role in managing pain and discomfort⁶⁰. This was the third most commonly reported concern across all patients participating in the e-HNA in London. When the data is analysed by cancer type, this was the second most frequently highlighted issues for those with gynaecological, lower GI and lung cancers, with up to 34% of patients reporting this. It was the third highest concern for those with breast, head and neck and upper GI cancers, with as many as 32% of patients highlighting this as an issue.

Additionally, difficulties with moving around and walking are amenable to rehabilitation⁶¹ and were reportedly the sixth most common concern across London. However, for those with haematological cancers, this represented the third most frequent concern with 26% of patients raising it. 19% of those with gynaecological cancers and 23% of those with sarcoma highlighted movement as an issue, making it the fourth most common concern for this patient group, and 25% of lung cancer patients also reported this as a concern.

Concerns with eating or appetite are a key reason for referring to rehabilitation services⁶² and this was the fourth most common issue for all patients across London, but was the most frequently reported concern for upper GI patients, with 29% of patients raising this. It was also the second most reported issue for of head and neck cancer patients, of whom 34% reported this issue. Additionally, 33% of lung patients and 15% of gynaecological cancer patients also reported this as a concern.

The data also demonstrates how these concerns change during different parts of the pathway. For example, examining the e-HNA data across London before and after treatment highlights a significant increase of 12% in the numbers of patients reporting tiredness, exhaustion or fatigue. The numbers of patients reporting pain or discomfort also increased by 3% from before and after treatment, highlighting this as a long-term consequence of cancer and its treatment. Whilst there was no change in those reporting issues with moving around and walking, the numbers described above demonstrate that

⁵⁹ ibid

⁶⁰ ibid

⁶¹ ibid

⁶² ibid

this remains a significant long-term concern. Additionally, whilst the numbers of patients reporting eating and appetite as a concern decreased slightly by 2%, again the frequency at which patients highlighted this as an issue as described above, suggest that this remains a long-term concern for many patients. The highly personalised approach of cancer rehabilitation services in regularly assessing and re-assessing patients throughout all parts of the pathway and tailoring interventions as needed, highlights how well placed these services are in addressing these needs. Further details and analysis of this data is provided in Appendix A.

National Cancer Patient Experience Survey

The 2017 National Cancer Patient Experience Survey (NCPES)⁶³ demonstrates that although progress has been made in London across a number of domains, there remain many areas where further improvements are needed.

Macmillan Cancer Support⁶⁴ reported that:

'Although in general the experience of people with cancer is good, with respondents giving an average rating of 8.6/10 and improving over time, Londoners living with cancer report worse patient experience than people living with cancer in the rest of England'

London is leading the way in three main areas; patients reporting they had a named CNS, having enough nurses on duty, and providing access to research studies. However, Londoners report poorer experience than the rest of England in many aspects of cancer care, and the reasons for this are complex and multi-faceted. Importantly, analysis has revealed that Londoners from the most deprived areas report poorer experience than those living in the least deprived areas and minority ethnic populations report poorer experience than those who identify as white⁶⁵. These findings are important to consider when planning and delivering rehabilitation services, and emphasise the need for targeted action in London to address inequalities. N.B. a cancer inequalities strategy is being developed by TCST during 2019 and will give recommendations and an action plan.

The NCPES survey predominantly focuses on people during their acute hospital treatment episode, but includes a number of questions related to their care after treatment. Several of these questions are particularly pertinent to rehabilitation as they

⁶³The National Cancer Patient Experience Survey (2017),
<http://www.ncpes.co.uk/index.php/reports/2017-reports>

⁶⁴ Macmillan Cancer Support (2017), *Mind the gap: Cancer Inequalities in London*
https://www.macmillan.org.uk/_images/4057%20MAC%20Report%202017_tcm9-319858.pdf

⁶⁵ Ibid

relate to experiences of cancer care and quality of life. Some important results for London include⁶⁶:

- Across London only **22 – 38%** of patients across the five STPs reported that they were provided with a care plan
- **50 – 57%** of patients surveyed across London STPs reported being told about the long-term side effects of their treatment before their treatment, as well as the immediate side effects
- Between **69 - 76%** of patients reported receiving other information about the potential short and long-term side effects of treatment
- Additionally, **59 – 66%** of patients noted that they were offered practical advice and support in managing side effects of treatment
- **55%** of patients in London highlighted that their families or someone close to them were provided with all the information they needed to help care for them at home
- Of patients surveyed, **77 – 81%** reported that hospital staff provided them with information about the impact cancer could have on their day to day activities
- When asked if they were given enough support from health and social care services including district nurses and physiotherapists, during treatment, only **39 – 49%** of patients surveyed agreed that they were
- **52 – 59%** of patients reported that they had received enough support from health and social care following treatment

These results suggest significant gaps, both in terms of receiving the appropriate information about possible consequences of treatment in the short and long term, as well as in receiving the right amount of support to help manage these. This is also true of families receiving sufficient information to support loved ones at home. These gaps are likely to have a negative impact on cancer care experience, outcomes and quality of life. Cancer rehabilitation services are well placed to address these unmet needs and are integral to all cancer pathways. The results of the 2017 National Cancer Patient Experience survey can be broken down by STP and CCG and can be viewed [here](https://public.tableau.com/profile/transforming.cancer.services.for.london#!/vizhome/NationalCancerPatientExperienceSurvey2017London/Story1):

⁶⁶ Healthy London Partnership (2018), *National Cancer Patient Experience Survey 2017 (London)*

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

Cancer rehabilitation and AHPs

Previous work by NHS England in London⁶⁷ has shown that data on rehabilitation services in London is lacking. For commissioners, this means that decisions on rehabilitation services are being made without adequate data on available services, usage of current services, and unmet need.

‘Feedback from many stakeholders has indicated that CCGs are struggling with the commissioning of rehabilitation for many reasons including knowledge of what rehabilitation is and the scale of the problem, due to insufficient data;’⁶⁸ (pg. 25)

The report showed that data is being collected by individual services, but it is variable and not necessarily reported upward in a way that demonstrates impact. While the objective was to identify current service data collection, the finding was that:

‘There is uncertainty over the scale of need for rehabilitation and the current demand in London. There is a need for consistent datasets that measure citizen outcomes at a local level and can influence commissioning decisions and drive change.’ (pg. 30)

Key recommendations from the regional report include defining what good looks like, which will be supported by improving data to understand scale of need and current demand, and consistent datasets to measure outcomes and drive change.

Mapping of the specialist cancer Allied Health Professional workforce in London by both *London Cancer*⁶⁹ and *London Cancer Alliance*^{**70} (LCA) has shown a significant shortfall in specialist posts. LCA published their findings in 2014⁷¹ and the work of both organisations suggests some key challenges including a lack of profile of cancer rehabilitation within London, a shortfall in the specialist cancer rehabilitation workforce and inequalities in service provision. There is significant opportunity for improvements in cancer rehabilitation through the NHS England ‘Cancer Transformation Funding’ programme.

⁶⁷ NHS England (2015), *Improving Rehabilitation Services Programme Regional Report – London*

<https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2016/09/rehab-leads-report-london.pdf>

⁶⁸ *ibid*

⁶⁹ *London Cancer*: This was part of UCL Partners and was the integrated cancer system serving North East and North Central London and West Essex. It transitioned to become the UCLH Cancer Collaborative (Cancer Alliance for North East and North Central London) in September 2016.

⁷⁰ *London Cancer Alliance* (LCA): This was formed in 2011 as the integrated cancer system across West and South London. It has now been replaced by RMPartners (Cancer Alliance for North West and South West London) and the South East London Accountable Care Network.

⁷¹ London Cancer Alliance (2014), *Allied Health Professionals Workforce Mapping and Requirements*.

<http://www.londoncanceralliance.nhs.uk/media/88180/ahp-mapping-and-workforce-requirement-report-2014.pdf>

1.6 Personalised care delivery: examples of best practice in cancer rehabilitation

There are many examples of how cancer rehabilitation services in London are delivering on the personalised care agenda. Three different services are presented, all of which evidence a holistic, personalised approach to care, and demonstrate positive outcomes across a range of domains, including quality of life and cost benefits. Although TCST has a focus on adult services, the Paediatrics and Teenage Cancer Therapies service at UCLH is shown, as there is significant learning for adult services.

1.6.1 *Move More Wandsworth*

Physical activity services play an important role in improving quality of life and managing consequences of treatment. The Move More Wandsworth programme caters for patients at all stages of treatment, and is integrated with primary and secondary care, as illustrated in the case study shown in Figure 13.

Figure 13: Move More Wandsworth case study

Helping cancer patients become more active: Macmillan Move More Wandsworth

Macmillan Move More Wandsworth is a bespoke, community-based physical activity behaviour change service for people affected by cancer in Wandsworth, Merton and Sutton. Move More is open to all cancer patients in the area, and is delivered by physical activity specialists qualified in Cancer and Exercise Rehabilitation, and Motivational Interviewing.

Macmillan Move More Wandsworth is delivered by Enable Leisure and Culture's Health and Wellbeing Team. Participants are provided with an initial 1:1 with a Physical Activity Specialist (PAS). This focuses on their individual circumstances, motivations, goals and any potential barriers, including potential side effects from treatment and previous activity levels. During this session, the PAS uses motivational interviewing techniques to work with each participant to think about activities they enjoy and would be able to keep doing in longer-term. Building on this and the PAS' specialist knowledge around safe and effective activities, they work together to set SMART goals as part of an individualised plan.

'I think one of the things that is quite difficult and different it is to recognise that the trajectory isn't the same as exercising pre - cancer. I might not be stronger or fitter, but I got out of the house, I survived treatment and I'm still on my feet and moving. Talking things through regularly has helped me get to this point'

Patient

"Having initial consultation was absolutely helpful. I was really worried because I had done nothing for months, but it was good to talk to someone who understood that I hadn't always been like this, that I had a different life before this"

Patient

Consultations take place in community venues, e.g. libraries and community centres, to avoid the often-daunting nature of fitness centres. This also helps highlight the broad forms physical activity can take. This allows the team to work flexibly with participants of all abilities and helps sustain activity in the long-term, as participants focus on the activities they enjoy. Some focus on building up daily activities, such as walking or gardening, and others are signposted to a range of community activities.

All participants are offered ongoing support for 12 months to help improve and sustain activity levels. Each appointment is agreed with the participant according to their need for maximum flexibility. In-between appointments, participants are encouraged to monitor their progress using the Move More pack.

Evaluation of the programme shows that after 12 months, 83% of participants have increased their physical activity levels by an average of 292 minutes per week. Importantly, 83% of participants also reported improved quality of life and 75% reported reduced levels of fatigue. Participants also reported additional benefits of the programme, including increased confidence, improved physical function and social support.

1.6.2 Macmillan Cancer Psychological Support, St George's NHS Foundation Trust

Figure 14: Macmillan Cancer Psychological Support at St George's NHS Foundation Trust case study

Macmillan Cancer Psychological Support (CaPS), St George's University Hospitals NHS Foundation Trust

The Macmillan Cancer Psychological Support (CaPS) team provides specialist clinical interventions, information and support addressing the psychological components of cancer. They support patients and families throughout the whole cancer pathway, as well as colleagues, through training, supervision, consultation and joint-working.

The team ensure that the psychological needs of patients affected by cancer are placed front and centre within their wider cancer care, promoting parity of esteem between physical and mental health care. The team offer a range of evidenced based and tailored interventions which patients opt in to through a making process. The service is open to self-referrals and regularly uses patient feedback to inform improvement. The service is integrated within cancer pathways and work closely with members of the cancer MDT to ensure psychological thinking is embedded throughout. The team also work closely with primary care and the third sector to facilitate continuity in psychological support between acute and community care.

The team has demonstrated statistically significant increases in functioning and quality of life, and when appropriate has supported patients to experience statistically significant reductions in anxiety and depression related to their cancer or its treatment. Further case studies show improved treatment adherence, reductions in unnecessary GP and A&E attendances, reduced pressure on mental health services, and reductions in avoidable delays to discharge.

"I would be costing the system so much more money if I hadn't had the help. I wouldn't have a job, my daughter probably wouldn't be living with me and I would probably have got ill again. I would likely have ended up in hospital because I would have attempted suicide"

Patient

shared decision-


1.6.3 Paediatrics and Teenage Cancer Therapies, University College London Hospital NHS Foundation Trust

Figure 15: University College London Hospitals NHS Foundation Trust Paediatrics and Teenage Cancer Therapies case study

University College London Hospitals NHS Foundation Trust Paediatrics and Teenage Cancer Therapies

The Paediatrics and Teenage Cancer Therapies team provide care to children and teenagers with cancer both as inpatients as well as to teenagers and young adult as outpatients at the UCH Macmillan Cancer Centre. The team includes occupational therapists, physiotherapists, an exercise in cancer physiotherapist and a therapy assistant.

The Therapies team works with patients to enable them to do the things they enjoy most. Their personalised care aims to increase functional outcomes, improve health and wellbeing, and facilitate safe and effective discharge planning.



'You have been motivational especially when there have been days that I have felt like not getting out of bed. The way in which you have engaged with me has made me look at therapies in a completely different way. I never realised that this important part of my recuperation after months of chemo could have been this enjoyable.'

Patient

services.

The team regularly use patient feedback to improve care and adapt their approach in line with patient need. For example, the team recently implemented an exercise initiative called #JOGLE, in which staff support patients to use an exercise bike during gaps between appointments. By encouraging self-management, this has reduced the need for 1:1 physiotherapy appointments.

The team recently developed #AmputeeBear, a child-friendly storybook illustrating a bear's journey from diagnosis to post amputation, to encourage questions through play and provide clear expectations to the patient and their family, contributing to early mobilisation and discharge. The team are working with a charity to create a similar storybook for all children's cancer

2. Key findings, Recommendations and Next Steps

2.1 Key findings

“There is recognition of the importance of cancer rehabilitation services and the nature of the service they provide. Enough funding must be provided to these services to allow adequate staffing for service provision”.

**Service User,
TCST Engagement Event**

The personalised care agenda and the move to integrated care systems provides significant opportunity for the transformation of cancer rehabilitation services in London and West Essex.

Stakeholder engagement work throughout this project has consistently shown the importance, and value of, cancer rehabilitation for patients, carers, and the wider healthcare system. Over the last three years we have completed scoping work and completed a work plan which included mapping of services, creation of a minimum dataset and development of service improvement tools. We believe our outputs have the potential to drive the transformation of cancer rehabilitation services in London, and ensure the delivery of high quality personalised care.

“None of the services join up or seem to communicate with each other.”

**Service User,
TCST Engagement Event**

There are many great cancer rehabilitation services in London, some of which are discussed within this guidance. Despite this, there remains variation in access to, and provision of cancer rehabilitation services in London and West Essex. Our mapping work has outlined the range of services across five

STPs including referral criteria and what is provided for users. It appears there are significant unmet needs for people living with and beyond cancer as many services provide care only for certain tumour groups, at certain stages of the pathway and in acute settings. It has not been possible to determine exactly how all cancer rehabilitation services are being commissioned. Much more needs to be done to ensure that all people living with and beyond cancer get their rehabilitation needs assessed at all key stage of the pathway and are referred early and appropriately to cancer rehabilitation services.

“I want access to a therapist who specialises in cancer.”

**Service User,
TCST Engagement Event**

Better data collection on cancer rehabilitation is needed across London and West Essex. TCST has developed, piloted and socialised a minimum dataset for cancer rehabilitation services that has significant potential to reduce variation in service provision across

London. The dataset is designed to be collected by clinicians, has been well received, and has attracted significant interest from a range of stakeholders including AHP Leads in NHS England and the Wales Cancer Network. The minimum dataset has a wide range of benefits for commissioners, service providers and service users. There are significant challenges in implementing this dataset as IT systems are not currently in place to support implementation and clinical buy-in needs to be secured on a regional scale. Work is on-going with a wide range of partner organisations to further develop this work.

In addition, TCST and Macmillan Cancer Support have created a patient facing questionnaire designed to capture essential basic information about users' experience of using cancer rehabilitation services and the outcomes of care. This questionnaire is being hosted on the Macmillan eHNA portal and will undergo a UK wide 6 month

evaluation. This work has significant potential to further our knowledge of the use of cancer rehabilitation services in London (and nationally) and to influence decision-makers around the importance of good data to inform commissioning.

The TCST Service improvement tools have been developed through extensive stakeholder engagement and evidence building activities. The user voice has been at the heart of this work. The tools outline a clear framework for what good cancer rehabilitation looks like and what service components are needed for proactive, personalised, accessible and coordinated care to be delivered. The tools were well received by providers and users, and are thought to have a range of uses including raising the profile of rehabilitation services with senior managers, engaging with commissioners, undertaking service development activities and demonstrating patient centred care. A six-month national evaluation of the tools is now underway on the Macmillan Cancer Support website and findings will be used to refine the tools and determine if they have potential to be used for benchmarking purposes.

In addition to the specific findings from the three work-streams, there are some further findings from this work, which are important to the development and transformation of cancer rehabilitation across London and West Essex:

- The 'voice' of cancer rehabilitation is not always well represented at top table discussions and clinicians do not always feel enabled to influence commissioning decisions; there is a need to develop leadership roles to address this
- The Personalised Care agenda remains an important lever for improving access to, and provision of cancer rehabilitation and improving the metrics for London is an important enabler. There is great potential to improve engagement with AHPs and to have AHPs playing a more significant role in provision of Holistic Needs assessments, Treatment Summaries, Health and Wellbeing events, and Stratified Pathways of Care.

"Services should also be available to patient's family etc. It's not just about me as an individual; it's about my whole family who have been affected by the experience."

**Service User,
TCST Engagement Event**

2.2 Recommendations

This section includes recommendations that are directly linked to the 3 workstreams, and additional recommendations that support this work and will be needed to drive change at a system level.

Mapping

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.

Minimum dataset

2019/2020

- Cancer Alliances to support TCST and Macmillan in the collection of cancer rehabilitation data on the eHNA portal.
- Commissioners and Cancer Alliances to work in partnership with TCST and local cancer rehabilitation services to collect quality baseline data, in line with the TCST data recommendation report.

Service improvement tools

Phase one – 2019/2020

- Embed the service improvement tools into clinical practice. This will require endorsement from CCGs, STPs, Alliances and continued support from TCST for implementation.
- Cancer rehabilitation services to meet with senior managers/local commissioners to speak about their experiences with the tools, and about service improvement opportunities they have identified through the process

Phase two – 2020 and beyond

- As a next phase of this work, the tools could be used to allow benchmarking between services. This would require infrastructure that can support this, such as the NHS Improvement Model Hospital.

Other integrated care system recommendations

- CCGs, STPs and Alliances to work with TCST to improve the information available to service users on how to access cancer rehabilitation services
- All CCGs, STPs, Alliances to identify a 'rehabilitation champion' to ensure rehabilitation is given 'parity of esteem' at top table conversations and is fully considered in all decision-making about the care of people living with and beyond cancer
- London CCGs, STPs and Alliances to focus on working toward achievement of national and local targets for Living with and Beyond Cancer metrics to contribute to addressing the personalised needs for people with cancer
- CCGs, STPs, Alliances to work with TCST to promote the role of AHPs in personalised care interventions (Holistic Needs Assessments, Treatment Summaries and Health and Wellbeing Events) and Stratified Care Pathways.
- CCGs and STPs to gather information on how cancer rehabilitation services are being commissioned.

2.3 Next Steps

The next steps for this work are to develop a detailed implementation plan and TCST resource will be needed to support implementation. The next steps include:

- TCST and Macmillan Cancer Support (including Macmillan GPs, Trust Recovery Package Managers, Communities of Practice and London Macmillan partnership managers) to raise awareness and profile of cancer rehabilitation in London.
- 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 (CCB) in Winter 2019.
- TCST & Macmillan Cancer Support to conduct a 6 month evaluation of London eHNA data on cancer rehabilitation and report findings back to LWBC Partnership Board and CCB (May– Dec 2019)
- TCST to continue to work with ALBs and other partner organisations to explore opportunities for wider scale piloting of a minimum dataset (ongoing)
- TCST to refine the service improvement tools following a 6-month evaluation period (June – August 2019)
- TCST will continue discussions with Macmillan Cancer Support and partner organisations such as NHS England/Improvement to explore the potential for benchmarking cancer rehabilitation across services in London.

3. Developing the Guidance

3.1 Cancer Rehabilitation scoping work

“Patients should have access to a holistic system that enables them to progress and deal with the problems that have resulted as a result of their treatment. Whether that be loss of physical function; whether it be psychological issues; or just continuing education of their problem”.

“Commissioning processes make it difficult for people to access care”.

“Certainly at the moment it doesn’t really feel like everyone necessarily knows what everybody else is commissioning”.

Quotes from attendees at focus group meetings (2016)

This work was undertaken by the Transforming Cancer Services Team (TCST) for London between April and December 2016 to better understand the scope of cancer rehabilitation services in London and to inform the development of comprehensive Integrated Care System Guidance. The work was overseen by a multidisciplinary Task and Finish (T&F) group, and a [report](#) was published in February 2017⁷².

The report was targeted primarily at commissioners but also providers, service users, the third sector and others. Although the focus of the work was on cancer rehabilitation in London, it became increasingly clear that the findings have relevance beyond cancer and beyond London.

TCST identified clear and consistent messages around the issues and challenges with cancer rehabilitation, and how these could be tackled with Integrated Care System Guidance. It was clear that intelligence is lacking on what cancer rehabilitation services are available in London, how they are being commissioned, what data is being captured by these services and how services are being quality assured and developed.

‘Lack of data on cancer rehabilitation services makes it difficult to demonstrate the impact and benefits of services, thus increasing the challenge for service development.’ (pg. 26)

In summary:

- The commissioning of cancer rehabilitation in London is fragmented and poorly co-ordinated and this can leave services vulnerable with a consequent impact on patient care.
- There is an urgent need for Integrated Care System Guidance that is accessible and easy to use, develops a shared understanding of what good looks like and how it should be commissioned, provides a convincing economic case for

⁷² TCST (2016) Cancer Rehabilitation: a scoping report for London

<https://www.healthylondon.org/wp-content/uploads/2017/11/Cancer-rehabilitation-a-scoping-report-for-london.pdf>

investment, advises on data and metrics to improve evaluation of services, and provides relevant local data to inform decision making.

- Moving forward will require a 'step change' in thinking away from a traditional medical model approach, and towards a more 'rehabilitative' way of delivering care.
- Implementation of the guidance will be complex and challenging but can be supported by linking cancer rehabilitation to national and regional directives.

A work-plan for 2017/18 was developed to produce comprehensive Integrated Care System Guidance, a suite of resources to support implementation, and on-going clinical leadership to champion cancer rehabilitation in London. The work-plan was ratified by the London Living With and Beyond Cancer Board in March 2017. Funding for the Macmillan Rehabilitation Clinical Lead post was secured from Macmillan Cancer Support in December 2016 to support work until December 2018. Additional funding was secured in December 2018 to support an extension until March 2019.

3.2 Cancer Rehabilitation Steering Committee

A multidisciplinary Steering Committee was established comprising many members from the previous T&F group. The group was pivotal in providing subject knowledge and 'on the ground' experience and ensured the project had relevance and appropriate direction.

The group was chaired by Karen Robb and included TCST, service users, provider organisations, commissioning, and the third sector. TCST also worked closely with NHS England, NHS Improvement, Health Education England, NHS Digital and Public Health England throughout this work. Members met ten times between March 2017 and March 2019, with some of the work done virtually. See Appendix B for the membership of the group.

The Committee agreed that work was needed in three main areas; mapping of cancer rehabilitation services in London, development of a minimum dataset to capture key metrics on cancer rehabilitation and development and piloting of a benchmarking/service improvement tool.

3.3 Cancer Rehabilitation Task & Finish (T&F) groups

Three T&F groups were established to carry out the project. An additional shorter-life working group was established in January 2019, see below.

3.3.1 Mapping

This group was led by Georgina Wiley, Macmillan Project Facilitator for LWBC between December 2017 and June 2018 and then by Sophie Lansdowne, Macmillan Project Manager for LWBC between November 2018 and March 2019. The membership of the group is shown in Appendix C.

The aim of the T&F group was to:

- Design and oversee a comprehensive mapping of cancer rehabilitation services in London and West Essex
- Produce a report with key findings and recommendations for London
- Champion improvements in minimum data collection for cancer rehabilitation
- Provide regular feedback to the Steering Committee and relevant Board meetings.

3.3.2 Minimum dataset

This group was led by Dr Karen Robb, Macmillan Rehabilitation Clinical Lead and membership of the group is shown in Appendix D The aim of the group was to:

- Report on what data is routinely captured on cancer rehabilitation services in London
- Develop and pilot a minimum dataset in London
- Provide recommendations on data collection for London
- Champion improvements in data collection
- Provide regular feedback to the Steering Committee and relevant Board meetings.

3.3.3 Service improvement tools

This group was led by Georgina Wiley, Macmillan Project Facilitator for LWBC and membership of the group is shown in Appendix E The aim of the group was to:

- Review what tools are currently available
- Design, pilot and refine service improvement tools to support the commissioning, and provision, of high quality cancer rehabilitation services
- Produce a report with key findings and recommendations for London
- Champion service user involvement in the evaluation of cancer rehabilitation services
- Provide regular feedback to the Steering Committee and relevant Board meetings.

3.3.4 Examples of good practice

This group was established in December 2018 and was led by Sophie Lansdowne. Membership of the group is shown in Appendix F. The aim of the group was to:

- Design and judge a competition to identify examples of best practice in cancer rehabilitation in London
- Support the inclusion of best practice examples within the Integrated Care System Guidance
- Provide feedback to relevant Committee and Board meetings.

4. An overview of cancer rehabilitation services in London: a mapping of services and how they are commissioned

4.1 Summary

TCST has carried out a comprehensive mapping exercise of adult cancer rehabilitation services, including physical activity services, in London and West Essex to make recommendations for the provision and development of services in the region. Our full report is available [here](#) and should be read alongside this guidance.

Although the provision of cancer rehabilitation by AHPs is relatively well spread across the five STPs in London, there remain significant gaps in access, particularly in community settings. A similar picture exists for physical activity services. The biggest challenge experienced by providers is lack of funding and workforce constraints. It has not been possible to gather detailed information regarding commissioning of cancer rehabilitation services. More work is needed to triangulate findings from this work with the workforce mapping led by the Cancer Alliances, which is due for completion in Autumn 2019.

4.2 Methodology

The work was carried out by a T&F group, which included representation from each of the three Cancer Alliances. The mapping included services who addressed the effects of cancer and cancer treatment and which had a direct referral route. They included:

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

Two surveys were developed, tested with a selection of TCST stakeholders and then used to gather data on what services were available in London, and how they were commissioned. See Appendix G and Appendix H for the surveys. Telephone calls, desk research and sharing of information with senior leaders across London were used to quality assure the data. In addition, TCST 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.

4.3 Key Findings

In this section we will present the results of the mapping exercise by STP. This will include a map of services in each area and examples of best practice as identified through the TCST Cancer Rehabilitation Competition.

4.3.1 Summary of responses

Information was received from 19 Trusts. 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.

Despite best efforts, our methodology was unsuccessful in obtaining responses to the survey for commissioners. Where contact was established, a large number of the identified leads were not sure who the right person to speak to was, and/or were not able to supply information about specific cancer rehabilitation services.

4.3.2 Cancer rehabilitation services in London and West Essex

Interactive Map

Interactive maps of all services identified as part of this exercise was developed. These maps show services by STP and by service type. These are available here:

<https://www.healthylondon.org/resource/mapping-of-pan-london-cancer-rehabilitation-services/>

Cancer rehabilitation service by STP

Maps of all cancer rehabilitation and physical activity services identified as part of this exercise are provided below.

North Central London

Figure 16: Map of cancer rehabilitation services in North Central London

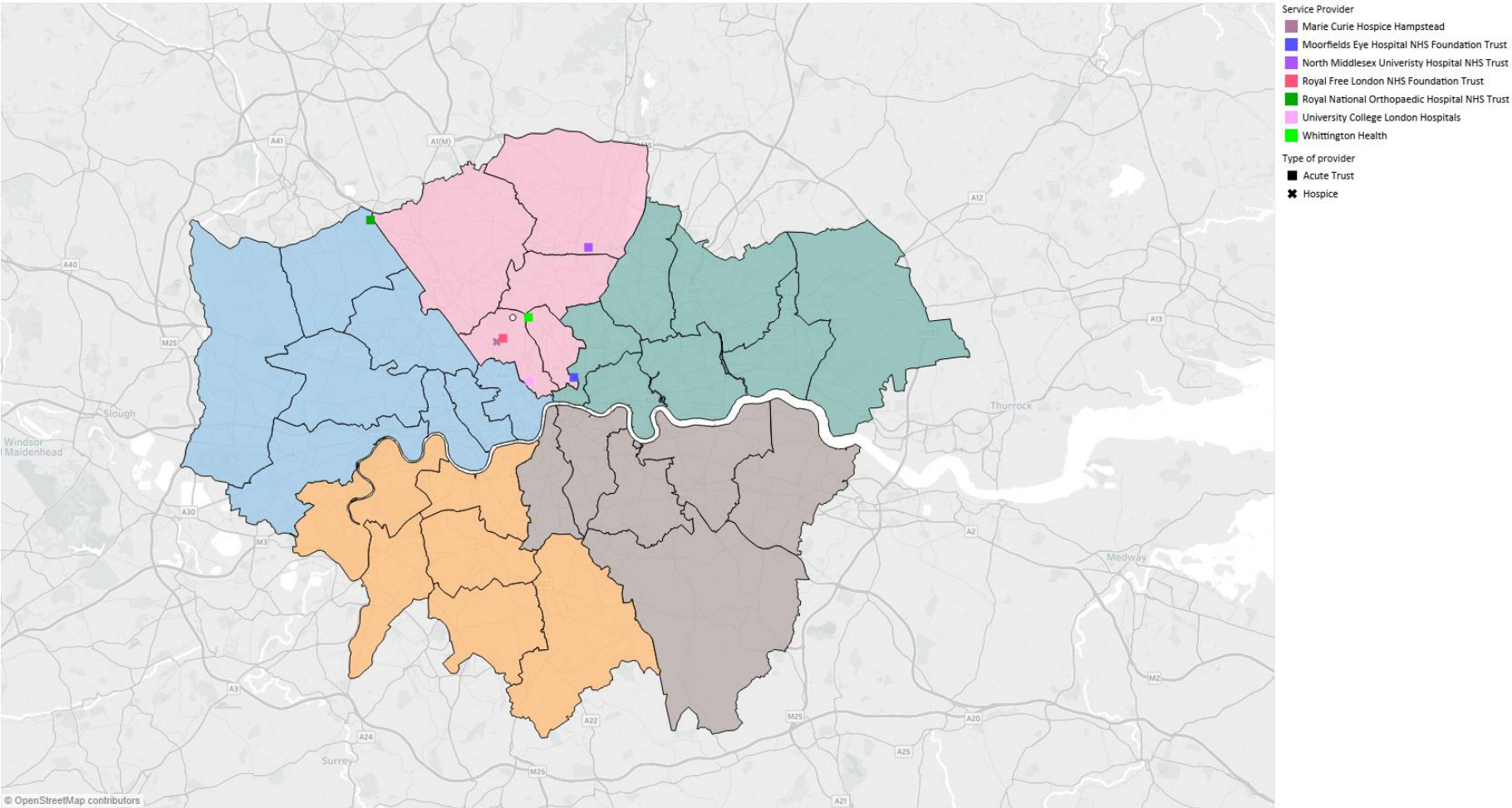
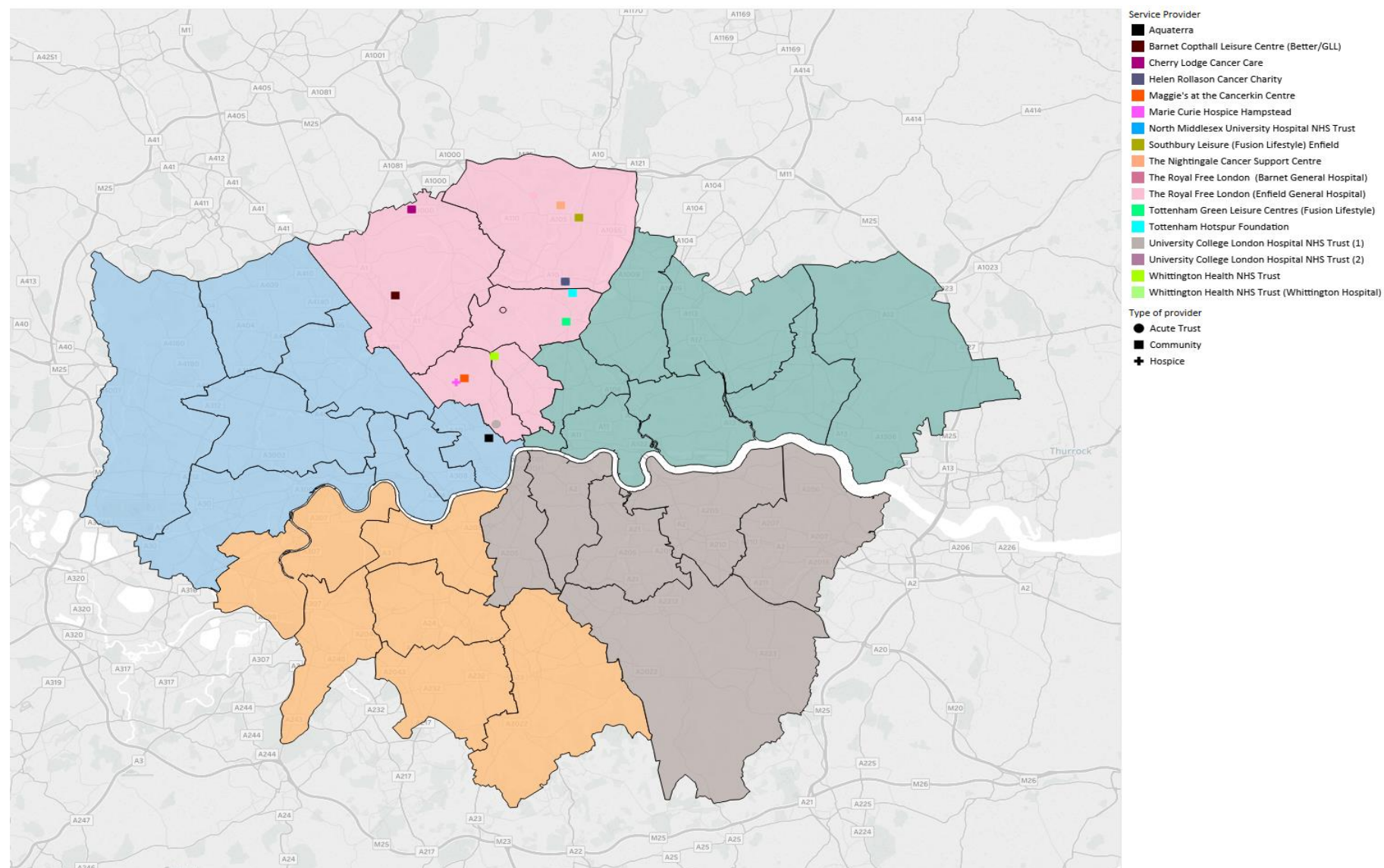


Figure 17: Map of physical activity services in North Central London



North East London

Figure 18: Map of cancer rehabilitation services in North East London

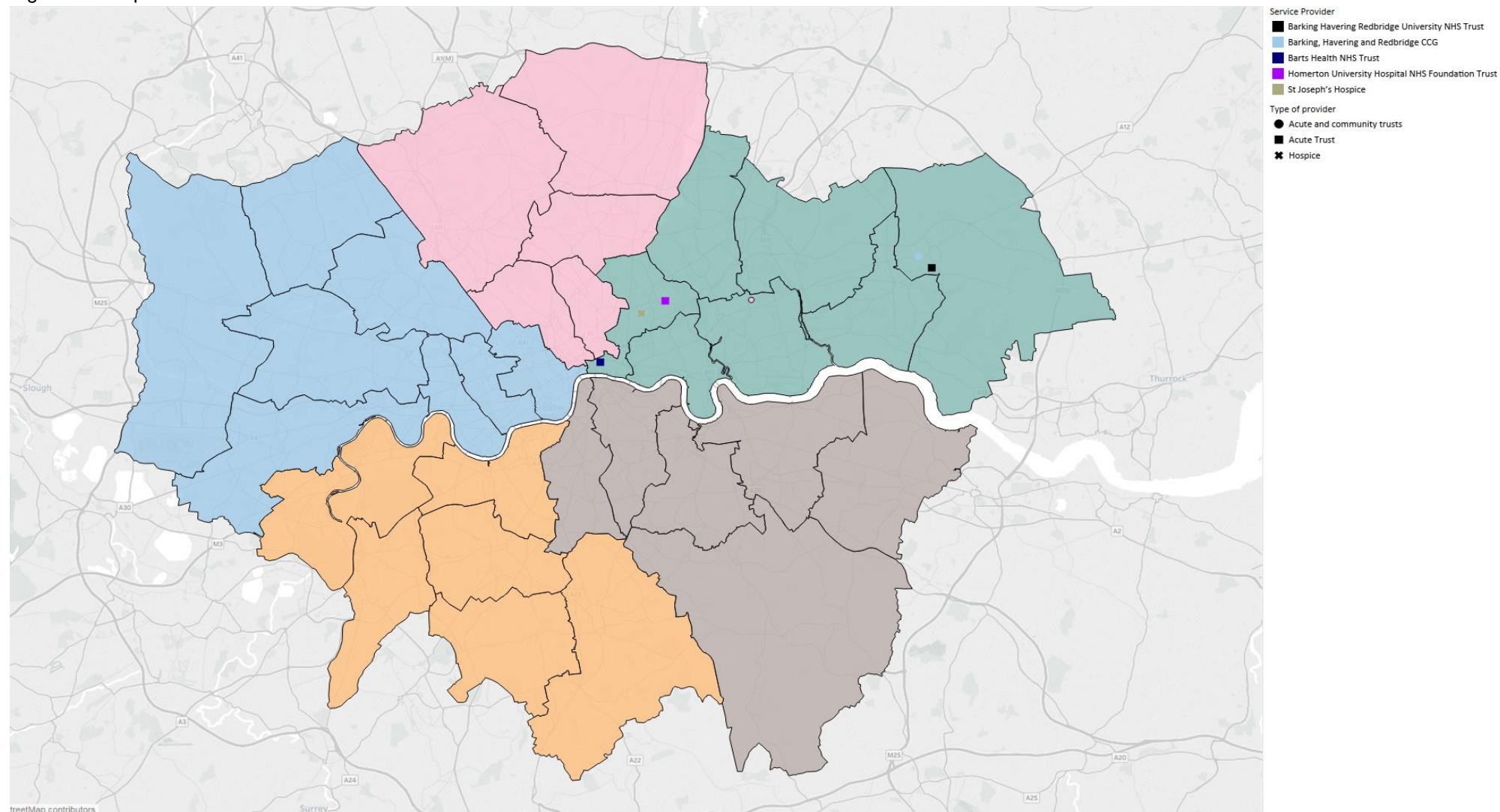


Figure 19: Map of physical activity services in North East London

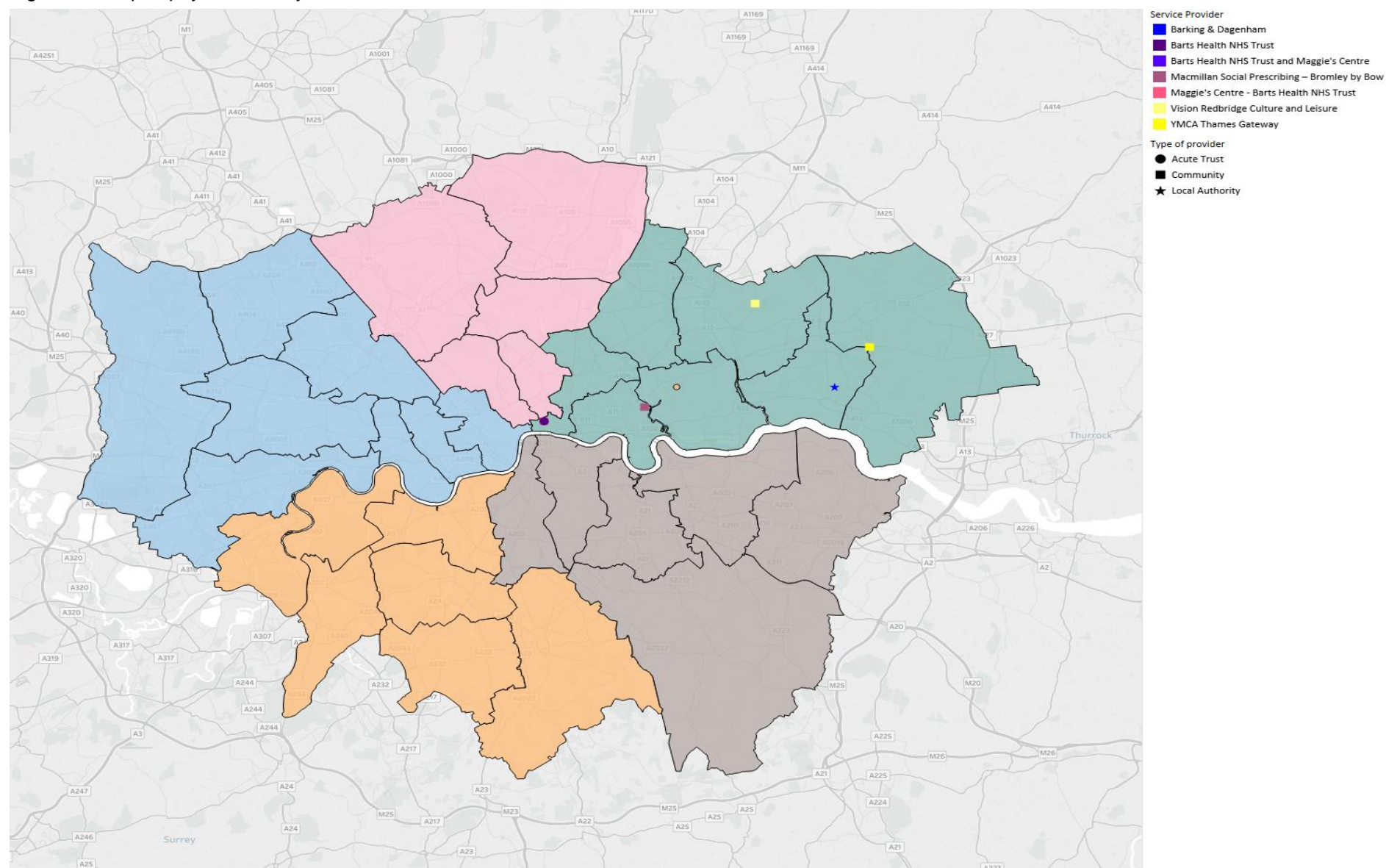


Figure 20: The Neuro-oncology Rehabilitation Service at St. Bartholomew's Hospital case study

The Neuro-oncology Rehabilitation Service at St. Bartholomew's Hospital

The Neuro-oncology rehabilitation service at St. Bartholomew's Hospital is a new service funded by Macmillan Cancer Support. The team provide intensive physiotherapy and occupational therapy to patients with complex neurological problems due to cancer or treatment.

The inpatient service was set up in response to the increasing incidence of neurological impairments affecting cancer patients. The team sits within the larger oncology therapy team and attend weekly ward rounds, MDT meetings and monthly neuro-oncology rehabilitation MDTs, to ensure rehabilitation is embedded within all aspects of care. To ensure a smooth transition to community rehabilitation services, team members frequently accompany patients to community assessments and complete joint discharge visits, particularly where community services are not specialist cancer services.

The team has demonstrated positive outcomes in patients' function, quality of life and experience of care. This integrated approach has improved education and support for the wider MDT, as well as for patients and their family. The service has also had a positive impact on patient flow, length of stay and costs for both secondary and primary care.

"My ability to walk again is thanks to the neuro-oncology team. The rehabilitation is absolutely marvellous it is probably the highlight of my day. I miss them at the weekend."

Patient

Figure 21: Moving Forward, YMCA Thames Gateway case study

Moving Forward, YMCA Thames Gateway

The Moving Forward Team provide a 12-week physical activity programme for all cancer patients following treatment. The programme includes weekly 1:1 gym sessions and access to health and wellbeing facilities. The team is made up of Level 4 Cancer Rehabilitation Specialists and Level 3 Fitness Instructors.

At the beginning of the programme participants meet with the instructor to talk about their goals and priorities. Participants' goals vary from having the strength to carry shopping to getting back to work. Instructors build personalised plans around individual priorities and abilities. Appointments are then provided flexibly depending on need and participants are encouraged to bring a buddy with them, free of charge, for extra motivation. Feedback has highlighted that the programme provides a supportive stepping stone following discharge and that it helps to achieve their goals in a timeframe which is suitable for individuals. The team provides additional support for participants in achieving their goals, for example in accompanying them to take part in outdoor runs and or walks.

"After my first tussle with breast cancer, the surgery and chemotherapy left me not only feeling weak physically but mentally I felt very fragile venturing out in the world again. The scheme of exercise you devised for me helped me regain my fitness and stamina and the fact that my husband could exercise alongside me and in effect cheer me on when I needed it was invaluable in that process"

Patient

North West London

Figure 22: Map of cancer rehabilitation services in North West London

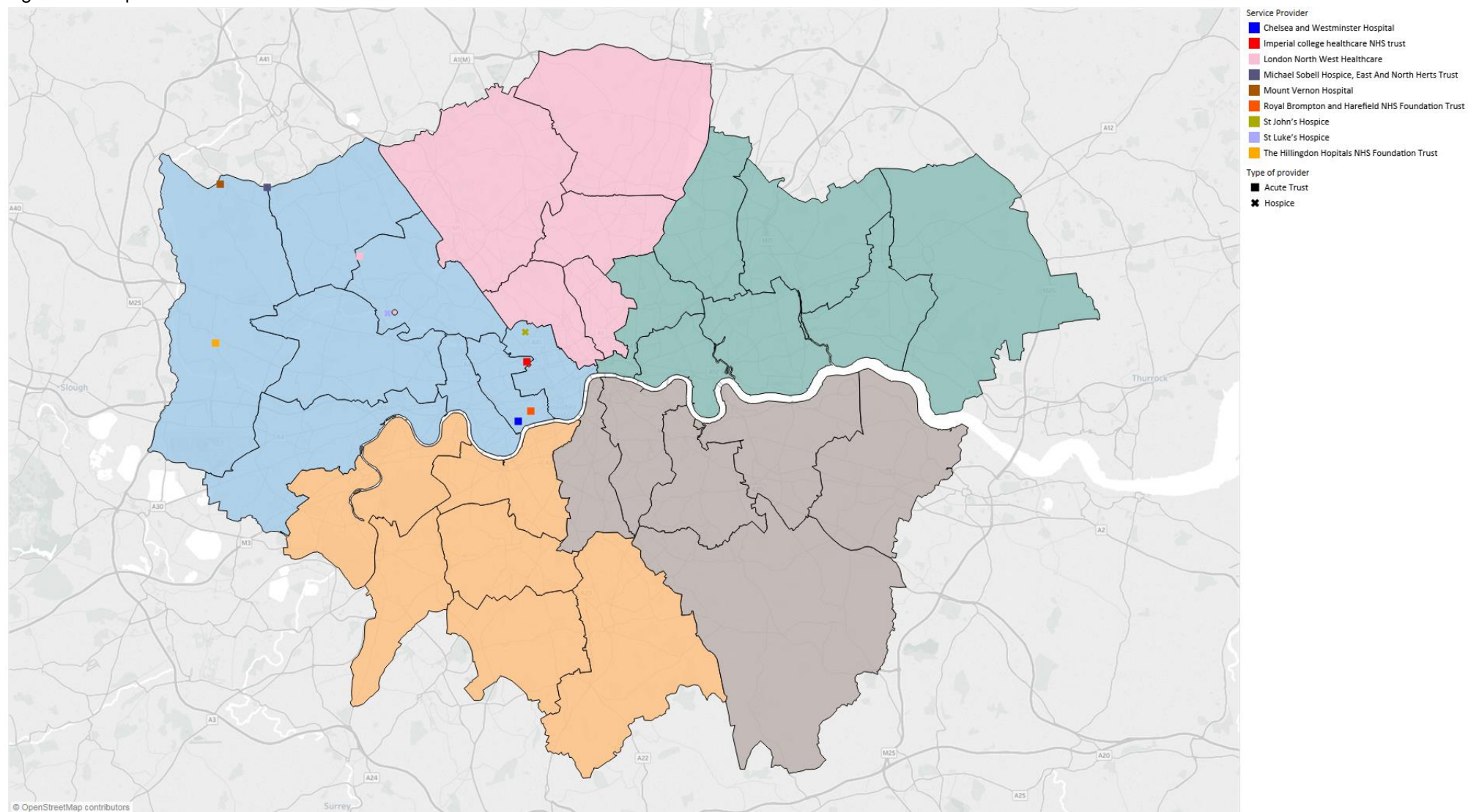
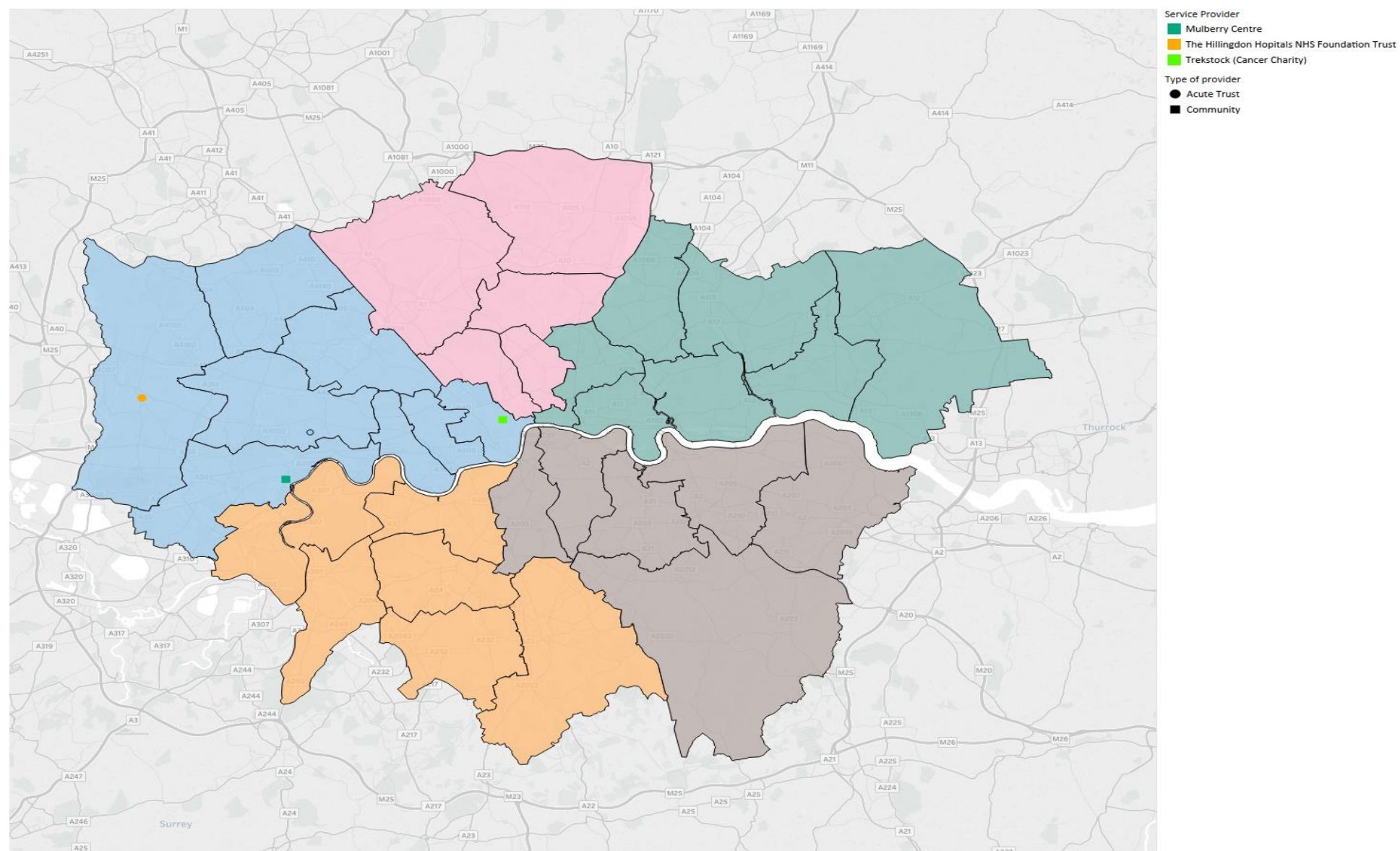


Figure 23: Map of physical activity services in North West London



South West London

Figure 24: Map of cancer rehabilitation services in South West London

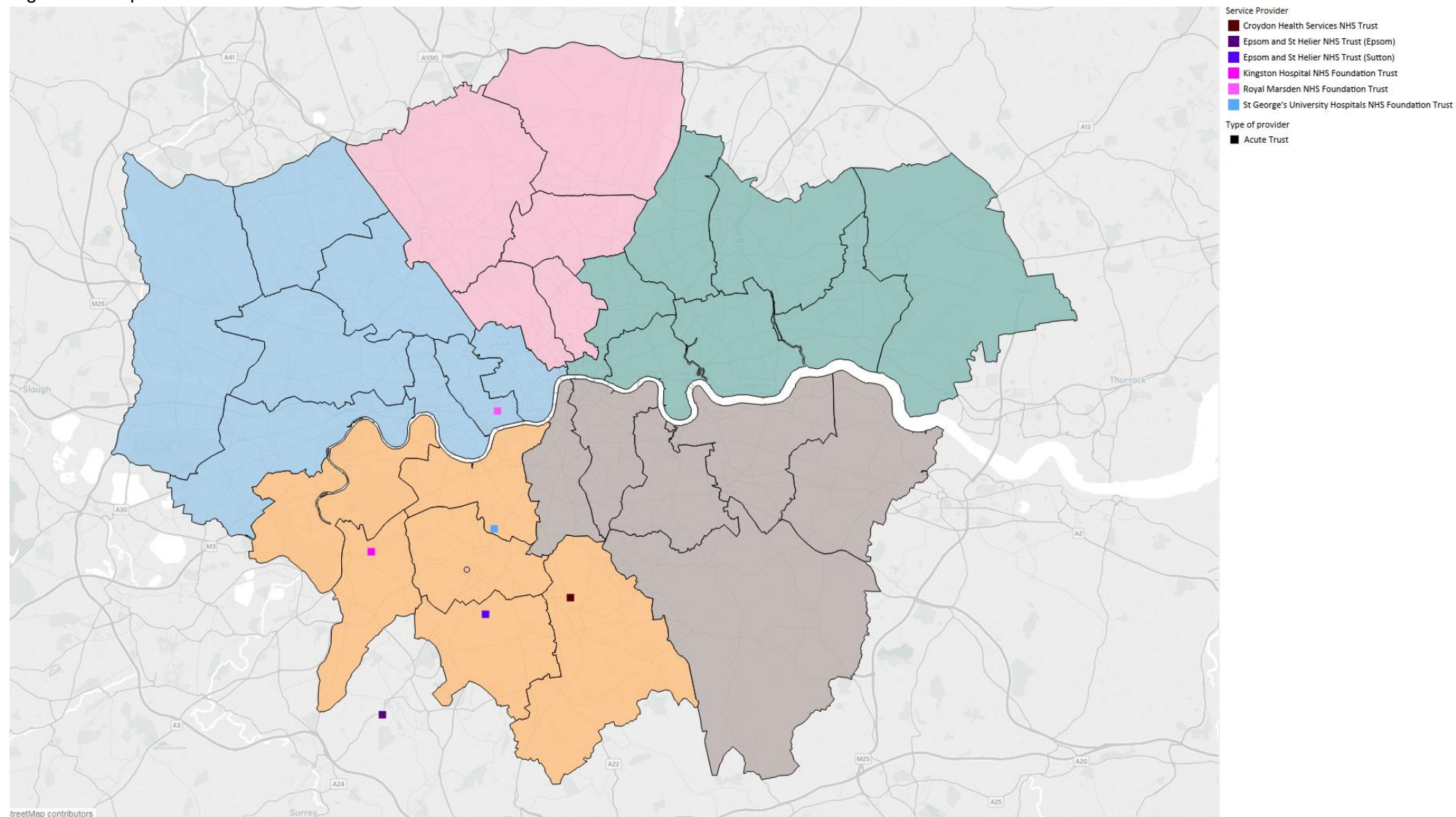



Figure 25: The Royal Marsden Paediatric and TYA Therapies Service case study

The Royal Marsden Paediatric and TYA Therapies Service

The Paediatric, Teenager and Young Adults Service at The Royal Marsden NHS Foundation Trust delivers inpatient and outpatient therapy for children, teenagers and young adults at all stages of the cancer pathway.

The team is made up of 6 AHPs, including specialist dietitians, physiotherapists, an occupational therapist and a speech and language therapist. Rehabilitation is personalised as needed, but can include nutritional support, relaxation therapy, fatigue management, swallowing and communication assessment, and support with mobility and exercise.

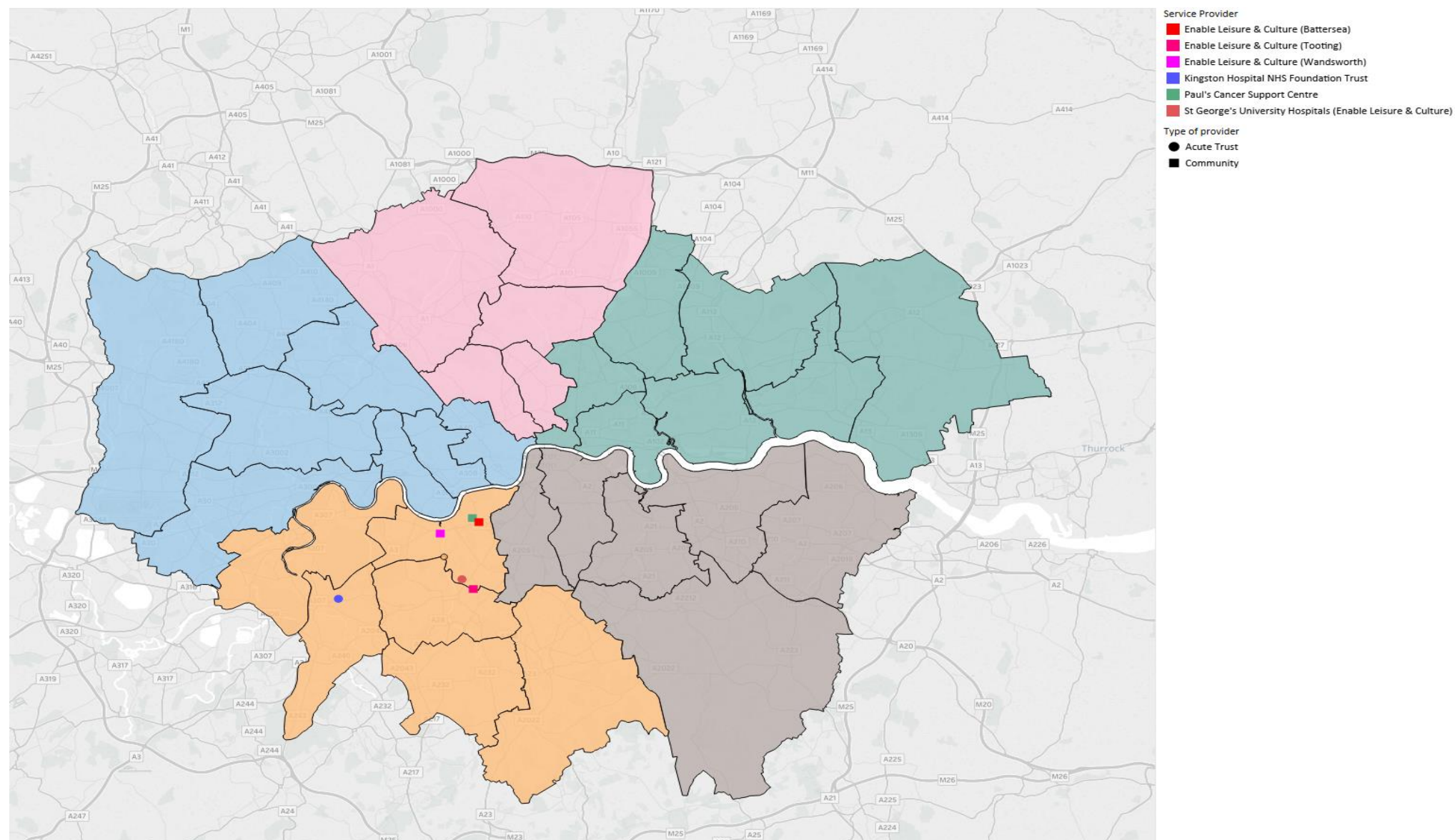
The team ensures an interdisciplinary approach to care, aiming to maximise shared-decision making, self-management and goal-orientated rehabilitation. As part of this personalised approach, the team support patients to remain engaged in the activities most important to them. Appointments are coordinated with other medical appointments and joint therapy assessments are provided to reduce the need for patients to repeat their story. The team also work with other local services to ensure appropriate referrals as early as possible.



"I have benefitted from the effects of physiotherapy, it definitely helped me manage and overcome pain and fatigue after chemotherapy, alongside a healthy diet ... exercising regularly during treatment and after helps you feel less poorly and makes recovery much faster. I believe physiotherapy is the only way to move forward and build my strength from scratch"

Patient

Figure 26: Map of physical activity services in South West London



South East London

Figure 27: Map of cancer rehabilitation services in South East London

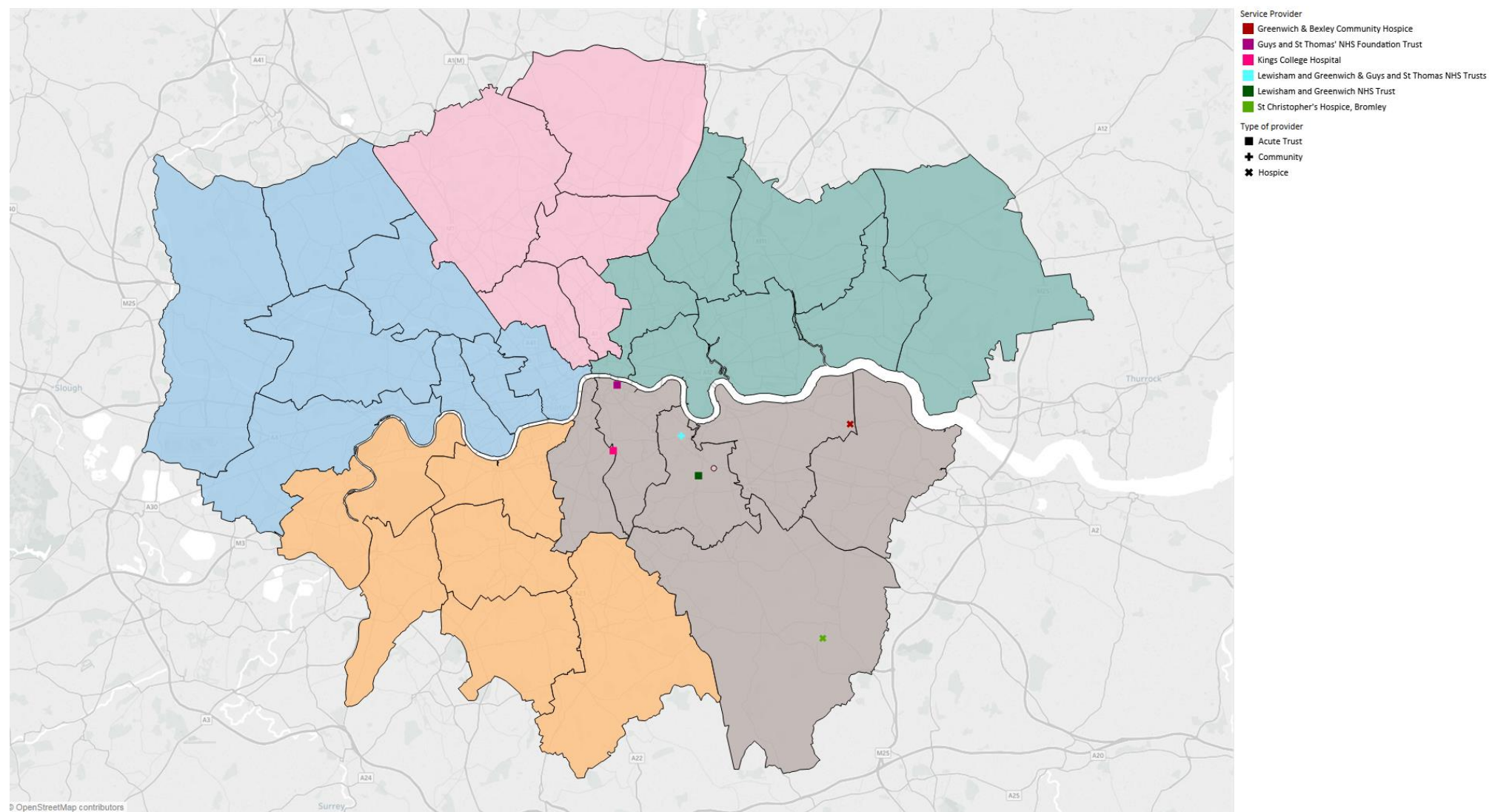


Figure 28: Map of physical activity services in South East London

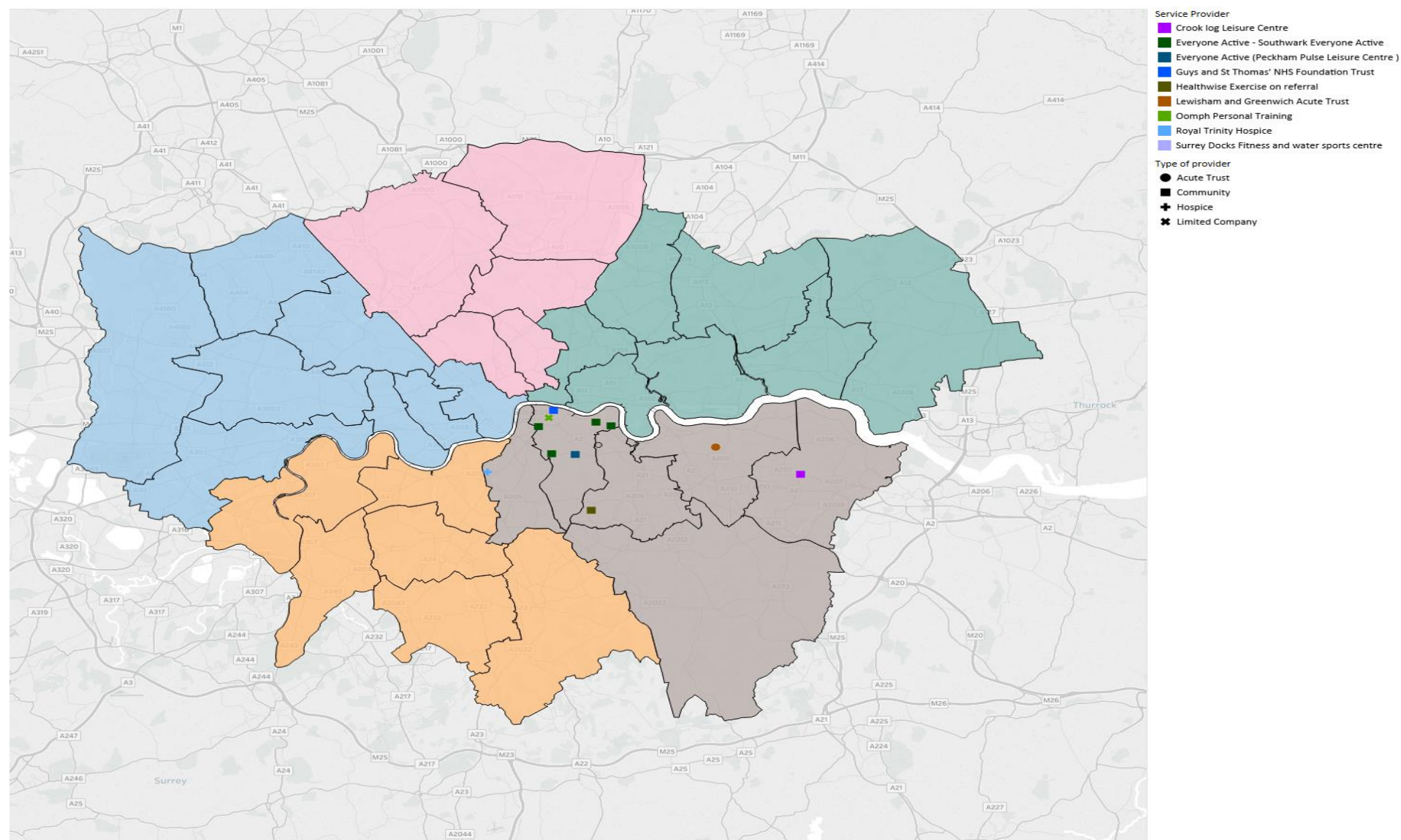


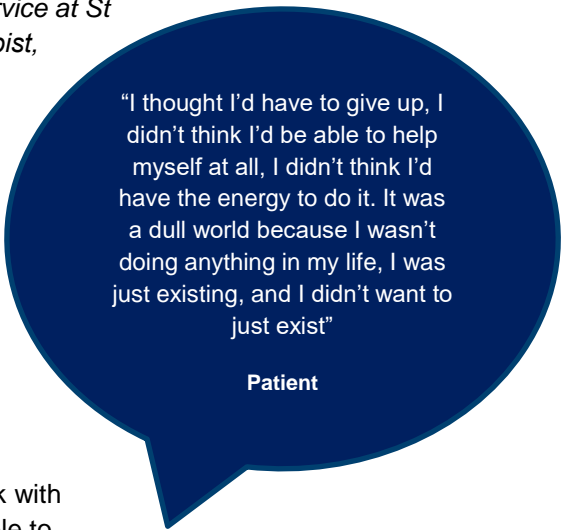
Figure 29: Living Well at Home Team, St Christopher's Hospice case study:

Living Well at Home Team, St Christopher's Hospice

The Living Well at Home Team is part of the rehabilitation service at St Christopher's. The team is made up of an occupational therapist, a physiotherapist and a rehabilitation assistant. They train volunteers to provide home-based rehabilitation and enablement for patients living with life-limiting conditions.

The team's volunteers provide support across Croydon, Bromley, Lewisham, Lambeth and Southwark. Volunteers are specially trained in rehabilitative approaches. They work alongside patients and carers, focusing on their individual goals, to empower them to live as independently as possible. These goals tend to focus on function, self-management, enablement and living well.

By providing this support at home, volunteers are able to work with those who are house-bound and might not otherwise been able to access palliative rehabilitation. Once patients are referred to the service, they are assessed by the team and subsequently matched with a volunteer who works with them on a weekly basis over 6-8 sessions. Following this, a therapist will see the patient for a review of their progress and rehabilitation needs.



"I thought I'd have to give up, I didn't think I'd be able to help myself at all, I didn't think I'd have the energy to do it. It was a dull world because I wasn't doing anything in my life, I was just existing, and I didn't want to just exist"

Patient

West Essex

Figure 30: Map of cancer rehabilitation services in West Essex

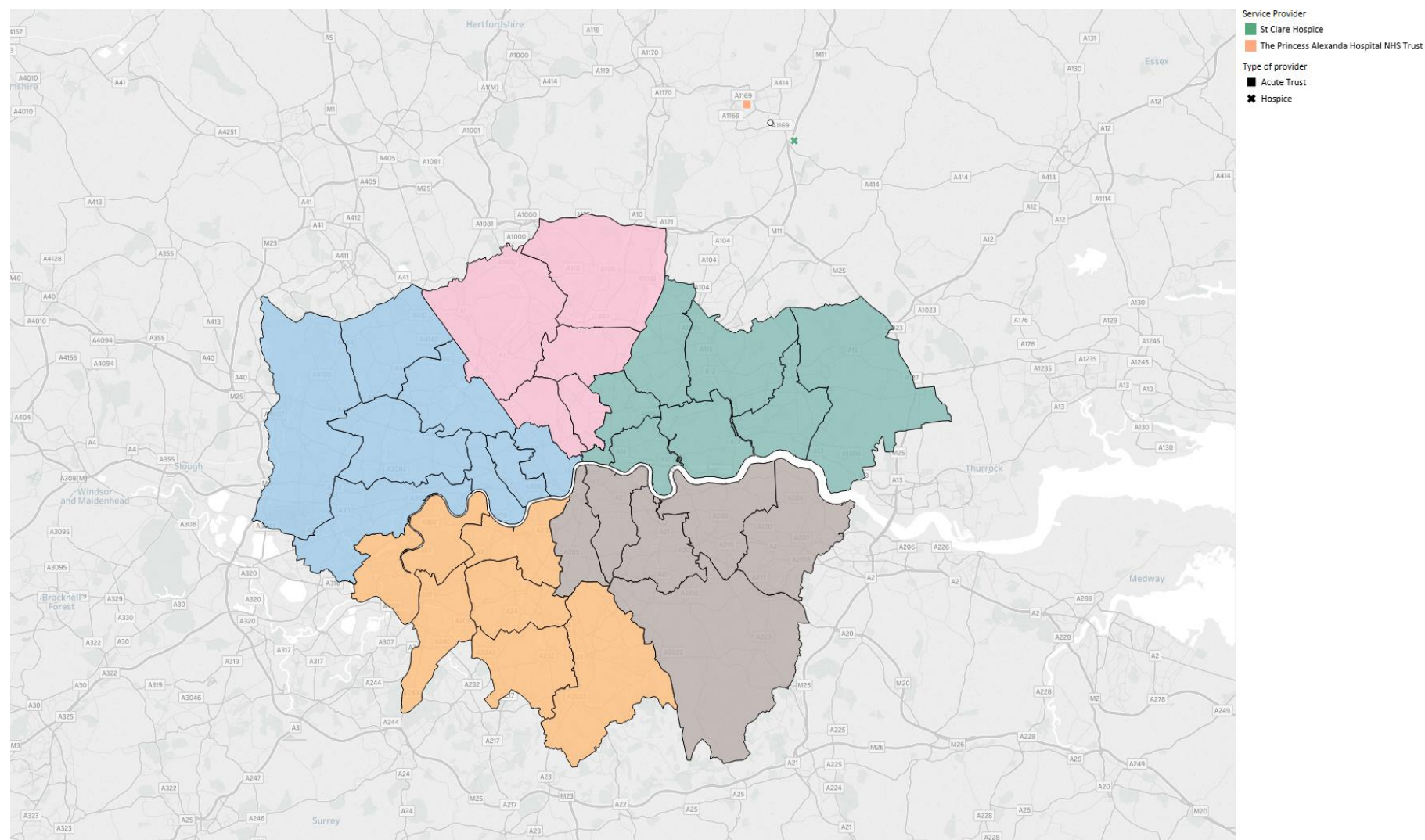
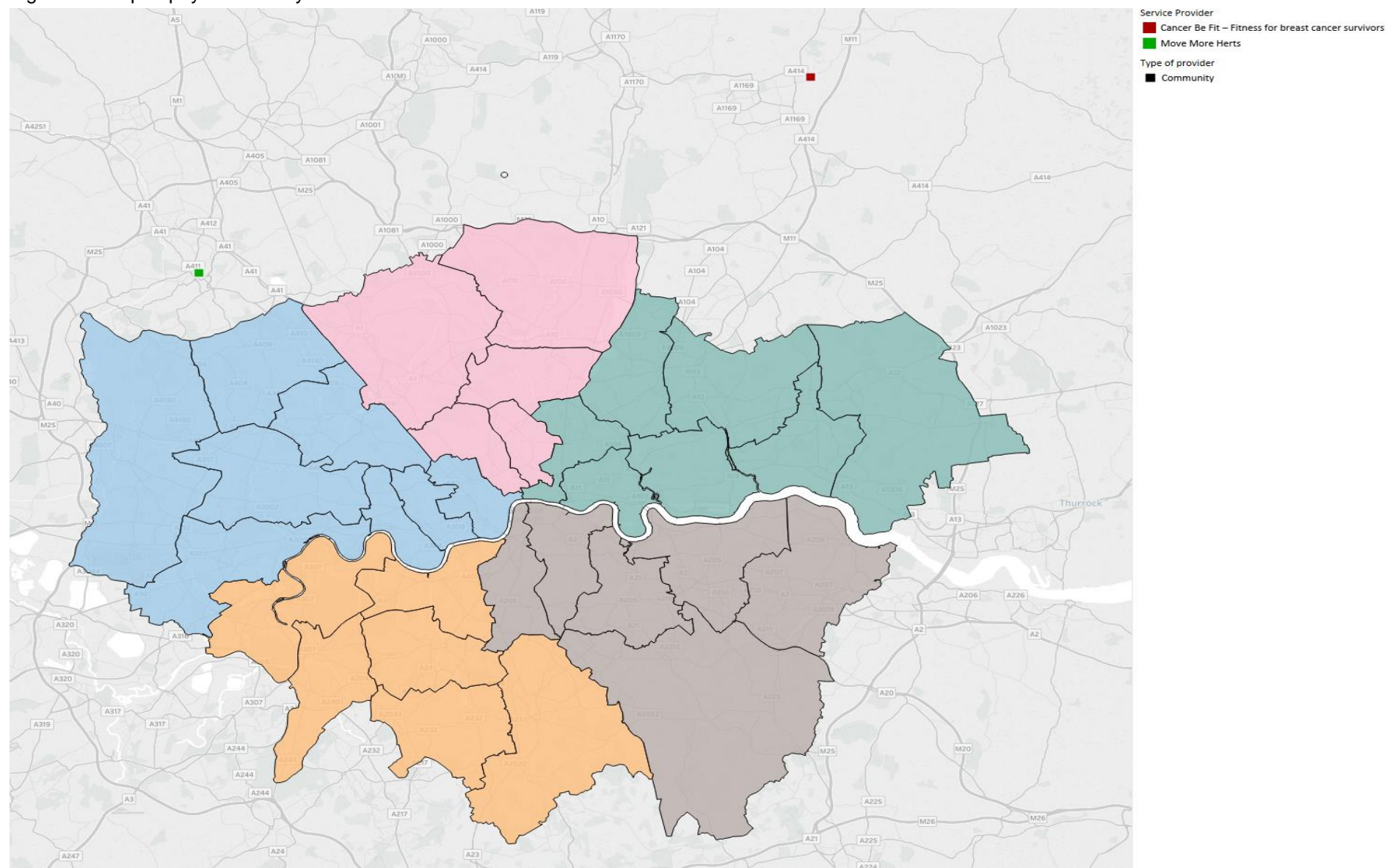


Figure 31: Map of physical activity services in West Essex



4.3.3 Summary of findings and limitations

- 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 greater range of cancer rehabilitation 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.

We identified several barriers to the development of cancer rehabilitation services and these included funding, lack of rehabilitation workforce development as other services grow and difficult demonstrating the impact of good rehabilitation. These are exemplified in the quotes below obtained from engagement events.

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

“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”

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

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

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

This mapping exercise had several limitations including:

- The lack of detailed intelligence around how cancer rehabilitation services are commissioned
- The inclusion criteria were not fully representative of the cancer rehabilitation workforce. We recognise the important role that psychological support services and other support 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 our mapping exercise.
- A loss of personnel resulted in a delay to this project between June and November 2018 and some momentum was lost.

4.4 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.

4.5 Next steps

- TCST and Macmillan Cancer Support (including Macmillan GPs, Trust Recovery Package Managers, Communities of Practice and London Macmillan partnership managers) to raise awareness and profile of cancer rehabilitation in London.
- 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 (CCB) in Winter 2019.

5. Capturing essential data on cancer rehabilitation services: a minimum dataset

5.1 Summary

TCST has developed, piloted and socialised a minimum dataset for cancer rehabilitation services that has significant potential to reduce variation in service provision across London. Our full report is available [here](#) and should be read in conjunction with this guidance. The minimum dataset has a wide range of benefits for commissioners, service providers and service users. Work is on-going with a wide range of partner organisations to further develop this work. See Appendix J for the final dataset.

In addition, TCST and Macmillan Cancer Support have created a patient facing questionnaire designed to capture essential basic information about users' experience of using cancer rehabilitation services and the outcomes of care. This questionnaire is being hosted on the Macmillan eHNA portal and will undergo a UK wide 6 month evaluation. This work has significant potential to further our knowledge of the use of cancer rehabilitation services in London (and nationally) and to influence decision-makers around the importance of good data to inform commissioning.

5.2 Methodology

5.2.1 Development of the minimum dataset

This work was carried out by the Minimum Dataset T&F group. In October 2017, TCST presented findings from a detailed scoping of what cancer rehabilitation data is available pan-London and made recommendations for pan London data collection and collation to support commissioners and other cancer rehabilitation stakeholders.

Specific recommendations for the dataset were drawn from interviews with thought-leaders and additional research carried out by TCST/Public Health England analyst Molly Loughran as part of the data scoping work. It was agreed that the dataset had to:

- Address challenges and complexities with current data collection
- Demonstrate impact and value of cancer rehabilitation
- Link with strategic priorities and existing workstreams
- Utilise learning from established datasets for a phased approach to implementation
- Represent the full spectrum of rehabilitation services.

The proposed minimum dataset included 17 measures falling under four broad categories:

- Patient demographics

- Provider information
- Information about the cancer
- Information about the treatment.

TCST recommended that implementation of the dataset should use a phased approach, which involved piloting the dataset, performing an audit, and iteratively revising and adding data items to the dataset.

5.2.2 Piloting the minimum dataset

The initial pilot was conducted using a paper version of the dataset and carried out by four different services in London over a four week period in October/November 2017. The aim of the pilot was to assess if the data collection was feasible.

A 'how to' guide (see Appendix L) was developed and the leads for each service below were tasked with completing a data form (see Appendix K) for every patient under their care who had completed their rehabilitation treatment, and returning it to Jason Petit, Senior Cancer Intelligence Lead at TCST for reporting. The four services taking part were:

- Oncology therapies team, Barts Hospital, Barts Health NHS Trust, London
- Community Head and Neck Team, Guys and St Thomas NHS Foundation trust
- YMCA Physical Activity service, Thames Gateway
- The Macmillan Social Prescribing Service Bromley by Bow Centre, London.

Results of the pilot were reported to the Cancer Rehabilitation Steering Group on 14th February 2018 where changes to the dataset were agreed and next steps were decided. It was agreed that data collection was challenging for three main reasons:

1. Difficulty extracting from systems
2. Differences in IT systems being used
3. The length of time it took to capture all the metrics needed.

There was strong agreement that a dataset was needed and important but that NHS IT systems were not currently in place to support capture, therefore further piloting was not indicated at that stage. It was also agreed that a short version of the dataset should be agreed with core items only. Further socialisation of the dataset (long and short versions) was recommended with key decision-makers within NHS England, and a range of other influential partner organisations.

5.2.3 Developing and socialising the dataset

The dataset was updated and presented in a format compatible with NHS Digital systems (see Appendix N) with a shortened version of the dataset outlined in the final column. Between March and November 2018, a range of meetings were held with Karen Robb, Jason Petit and a range of stakeholders to discuss the potential for the TCST

dataset to improve intelligence on the delivery of cancer rehabilitation services in London. The key stakeholders involved were:

- Andrew Murphy, Head of Cancer Datasets, Public Health England
- Thomas Kearney, Deputy Chief Allied Health Professions Officer, NHS England
- Andrew Brittle, Dany Bell and June Davis, Macmillan Cancer Support

The dataset was socialised at several meetings including:

- Pan London Cancer Intelligence Operational Meeting
- Cancer Delivery Board
- Cancer Commissioning Board
- LWBC Partnership Board
- Royal Marsden Partners LWBC Board and Royal Marsden Hospital therapies leads meeting
- Barking Havering and Redbridge Cancer Collaborative meeting
- Macmillan Cancer Support AHP Advisory Group
- Association of Chartered Physiotherapists in Oncology and Palliative Care winter conference
- South East London Living With and Beyond Cancer Steering Group

In addition, a WeAHPs Tweet Chat was dedicated to discussion of the TCST dataset (and service improvement tools) on 28th March 2019.

5.2.4 Developing a patient facing questionnaire

Due to the challenges experienced in the piloting of a clinician facing dataset (described section 5.3.2), TCST met with Macmillan Cancer Support to consider a different approach to data capture. It was agreed that a questionnaire held on the Macmillan eHNA portal could be used to capture basic data on how patients were using cancer rehabilitation services. It was agreed to base the questionnaire on key aspects of the minimum dataset, but acknowledged that there was a limit to the questions that could be included due to the potential burden on service users, and the design of the portal.

The following questions were agreed, and a full version of the questionnaire is shown in Appendix M.

1. What rehabilitation needs are you getting support for?
2. Do you have any other rehabilitation needs you are not receiving support for?
3. Who were you referred to for support with the above?
4. What treatment/advice/support did you receive?
5. In what setting did you receive your rehabilitation?
6. How effective was the rehabilitation you received? Please give a total score for all of it.
7. Do you need onward referral for further treatment/advice/support?
8. Have you got an onward referral for further treatment/advice/support?

9. If so where is this referral to?

5.3 Key findings

5.3.1 Minimum dataset

The TCST minimum dataset for cancer rehabilitation services has significant potential to reduce variation and improve the commissioning of cancer rehabilitation services in London. It has been well received and regarded as a purposeful set of metrics worthy of evaluation in London, despite the significant challenges that exist with IT systems. To our knowledge this is the first time a minimum dataset for cancer rehabilitation has been developed, piloted and socialised in England. There has been significant interest in this work from colleagues in national roles both in England and across the UK, and in cancer and non-cancer settings.

5.3.2 Macmillan eHNA questionnaire

The patient facing questionnaire on the Macmillan eHNA portal has significant potential to add to our knowledge and understanding of how services users are accessing cancer rehabilitation services and the outcome of these interventions. To our knowledge, this is the first pilot of it's kind nationally, and perhaps internationally,

We believe that the work we have undertaken to improve data collection has many benefits for the wider system including:

Benefits for Commissioners and Decision-makers

The dataset:

- Provides a comprehensive and meaningful set of metrics with which to gather baseline data on cancer rehabilitation services
- Allows detailed evaluation of patient demographics, type of care delivered and amount of care delivered
- Has potential to support future commissioning decisions and future service developments through better identification of need.

Benefits for Service Providers

The dataset:

- Allows detailed examination of the care they deliver to people LWBC including type, amount, where and to whom
- Supports audit and governance activities
- Supports conversations with commissioners and decision-makers around service development opportunities and gaps in services.

Benefits for Service Users

The dataset:

- Allows a clearer picture to be established on how cancer rehabilitation services are being accessed in London
- Allows evidence-based decisions to be made about the commissioning of cancer rehabilitation ensuring the provision of high quality care, which is based on need.

5.4 Recommendations

2019/2020

- Cancer Alliances to support TCST and Macmillan in the collection of cancer rehabilitation data on the eHNA portal.
- Commissioners and Cancer Alliances to work in partnership with TCST and local cancer rehabilitation services to collect quality baseline data, in line with the TCST data recommendation report.

5.5 Next steps

- TCST & Macmillan Cancer Support to conduct a 6 month evaluation of London eHNA data on cancer rehabilitation and report findings back to LWBC Partnership Board and CCB (May – Dec 2019)
- TCST to continue to work with ALBs and other partner organisations to explore opportunities for wider scale piloting of a minimum dataset (ongoing).

6. Evaluating and improving cancer rehabilitation services: service improvement tools

6.1 Summary

The TCST Service improvement tools have been developed through extensive stakeholder engagement and evidence building activities. The user voice has been at the heart of this work. The tools outline a clear framework for what good cancer rehabilitation looks like and what service components are needed for proactive, personalised, accessible and coordinated care to be delivered. The tools were well received by providers and thought to have a range of uses including raising the profile of rehabilitation services with senior managers, engaging with commissioners, undertaking service development activities and demonstrating patient centred care. A full report is available [here](#) and the tools are available [here](#).

6.2 Methodology

A task and finish (T&F) group was formed to focus on developing and piloting the tool(s). Two consultation events were held, one aimed at service users and one at service providers. Each event sought to understand the essential aspects of service delivery, the themes which should be included in the tool, and how it should be utilised. In addition, a range of key documents were considered.

A key finding from the consultation events was that two tools should be developed, a comprehensive tool for providers and a brief version for service users. In addition, it was decided that the tools should focus on service improvement. The T&F group was advised to develop a provider tool that would identify what good looks like, and that:

- Is easy to complete and will not be a burden on busy clinicians
- Is applicable to all cancer rehabilitation services (acute, community etc.)
- Includes measurable opportunity for improvement
- Includes aspects important to users, providers and funders
- Could be completed by clinical staff at all levels (therefore creating opportunity for more junior members of staff to undertake personal development opportunities)

6.3 Key findings

Service users and carers identified a range of issues which were central to the delivery of high quality cancer rehabilitation. A selection of feedback is included from engagement events held between January 2018 and June 2018 is shown below:

Current Issues:

When you're receiving cancer treatment and you are the centre of attention, you're not thinking ahead to the day when you're on your own and needing to access services and how you go about this."

"None of the services join up or seem to communicate with each other."

"There aren't enough resources given to services to support the care they are giving."

"It's about timing – once you have completed chemotherapy or radiotherapy the last thing that you want is to launch into rehabilitation but when you are ready for it the channels to access it may no longer be available."

"The after effects of cancer can last for a long time – it's not just 6 months to a year after treatment, I know people who may not need assistance straight away but two years later [they] do."

What service users want:

"There is recognition of the importance of cancer rehabilitation services and the nature of the service they provide. Enough funding must be provided to these services to allow adequate staffing for service provision".

"That the people involved are well informed, supportive and listen to what I'm really saying."

"I want access to a therapist who specialises in cancer."

"Matching your needs to the services which are available – a service professional knowing you is really important."

"Opportunities to share experiences with others."

"Services should also be available to patient's family etc. It's not just about me as an individual; it's about my whole family who have been affected by the experience."

"We don't just want to survive."

Some key themes were considered integral to the tools:

- Providing patient-centred, outcome focused care
- Accessible and timely service
- Coordinated care
- Good communication
- Compassion and understanding in care giving
- Staff providing specialist care

- Adequate resourcing

Information collected from both consultation events was similar with two exceptions:

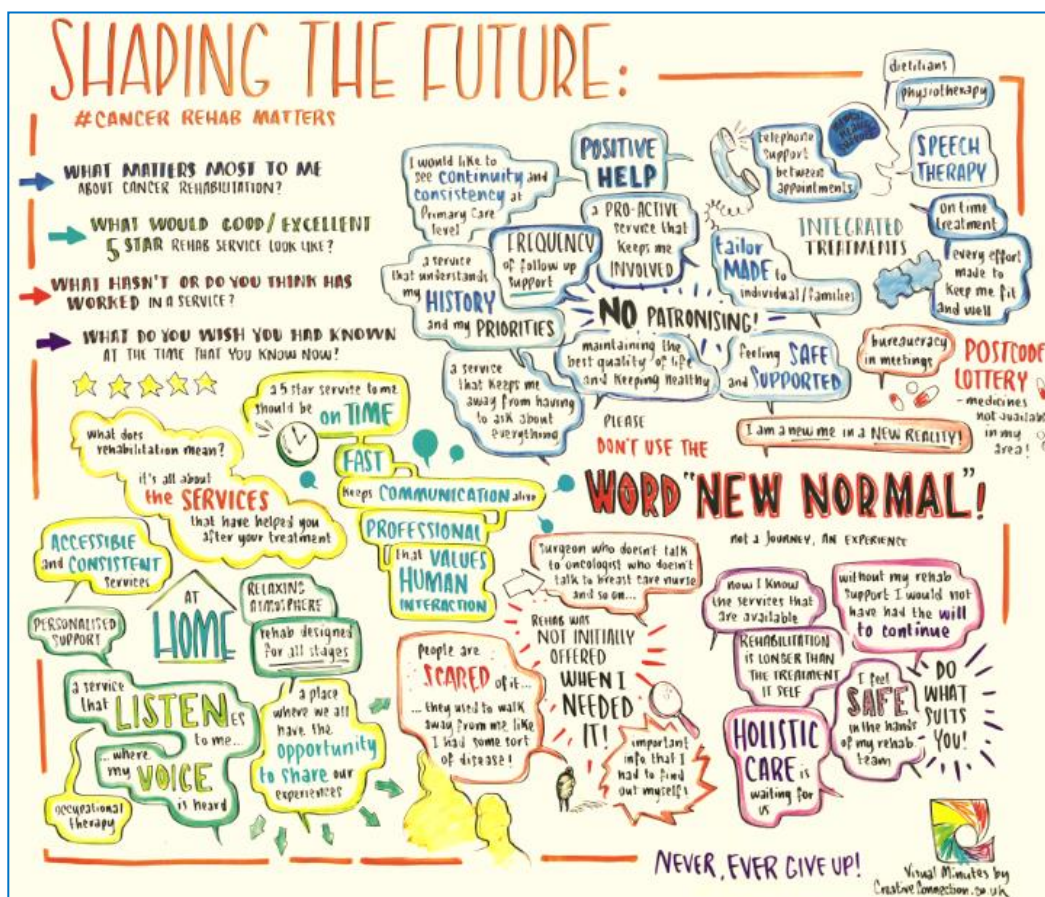
- Providers identified the practicalities of service provision including resourcing
- Users wanted access for carers and family, and access to others with lived experience.

In addition, providers felt the tools would give an opportunity to improve patient care and experience, build the evidence base for service development, and facilitate thinking time to focus on team objectives. They also wanted the opportunity to be able to benchmark themselves against other services. The tools were piloted in London across a range of cancer rehabilitation services and refined for relevance and usability before being finalised.

The patient voice has been at the heart of this work, and a visual mural representing what good cancer rehabilitation looks like from a patient perspective is shown below. A series of YouTube videos have also been produced showing what patients value about cancer rehabilitation services and an example of these can be viewed [here](#).

These innovative multifaceted tools have implications across the rehabilitation sector as part of quality improvement activity for providers, as well as supporting quality assurance for commissioners.

Figure 32: Mural from patient engagement event



Benefits for Commissioners

The tools:

- Provide a detailed overview of the cancer rehabilitation services they commission and how they are rated by providers themselves
- Provide opportunity to gain greater understanding of how users rate the services they are accessing
- Help identify innovative approaches to care, as well as areas for growth and improvement
- Provide opportunity to measure outcomes seen as important to users
- Provide future potential to benchmark a range of cancer rehabilitation services on a common quality framework.

Benefits for Service Providers

The tools:

- Can be used by services in a range of ways
- Can help raise the profile of rehabilitation with managers and commissioners, and demonstrate why rehabilitation is important
- Provide opportunity to measure outcomes seen as important to users
- Identify where their services are performing well and opportunities for improvement, including gaps in services
- Are measurable and allows opportunity to measure progress over time
- Contribute to organisational requirements around audit, governance and benchmarking.

Benefits for Service Users

The tools:

- Provide opportunity to give real time feedback to staff and services on aspects which matter most
- Provide a tangible way to see their feedback being incorporated into service improvement and benchmarking.

6.4 Recommendations

Phase one – 2019/2020

- Embed the service improvement tools into clinical practice. This will require endorsement from CCGs, STPs, Alliances and continued support from TCST for implementation.

- Cancer rehabilitation services to meet with senior managers/local commissioners to speak about their experiences with the tools, and about service improvement opportunities they have identified through the process

Phase two – 2020 and beyond

- As a next phase of this work, the tools could be used to allow benchmarking between services. This would require infrastructure that can support this, such as the NHS Improvement Model Hospital

6.5 Next steps

1. TCST to refine the tools following a 6-month evaluation period (June – August 2019)
2. TCST will continue discussions with Macmillan Cancer Support and partner organisations such as NHS England/Improvement to explore the potential for benchmarking cancer rehabilitation across services in London

7. Summary of next steps

The next steps for this work are to develop a detailed implementation plan and TCST resource will be needed to support implementation. The next steps include:

- TCST and Macmillan Cancer Support (including Macmillan GPs, Trust Recovery Package Managers, Communities of Practice and London Macmillan partnership managers) to raise awareness and profile of cancer rehabilitation in London.
- 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 (CCB) in Winter 2019.
- TCST & Macmillan Cancer Support to conduct a 6 month evaluation of London eHNA data on cancer rehabilitation and report findings back to LWBC Partnership Board and CCB (May– Dec 2019)
- TCST to continue to work with ALBs and other partner organisations to explore opportunities for wider scale piloting of a minimum dataset (ongoing)
- TCST to refine the service improvement tools following a 6-month evaluation period (June – August 2019)
- TCST will continue discussions with Macmillan Cancer Support and partner organisations such as NHS England/Improvement to explore the potential for benchmarking cancer rehabilitation across services in London.

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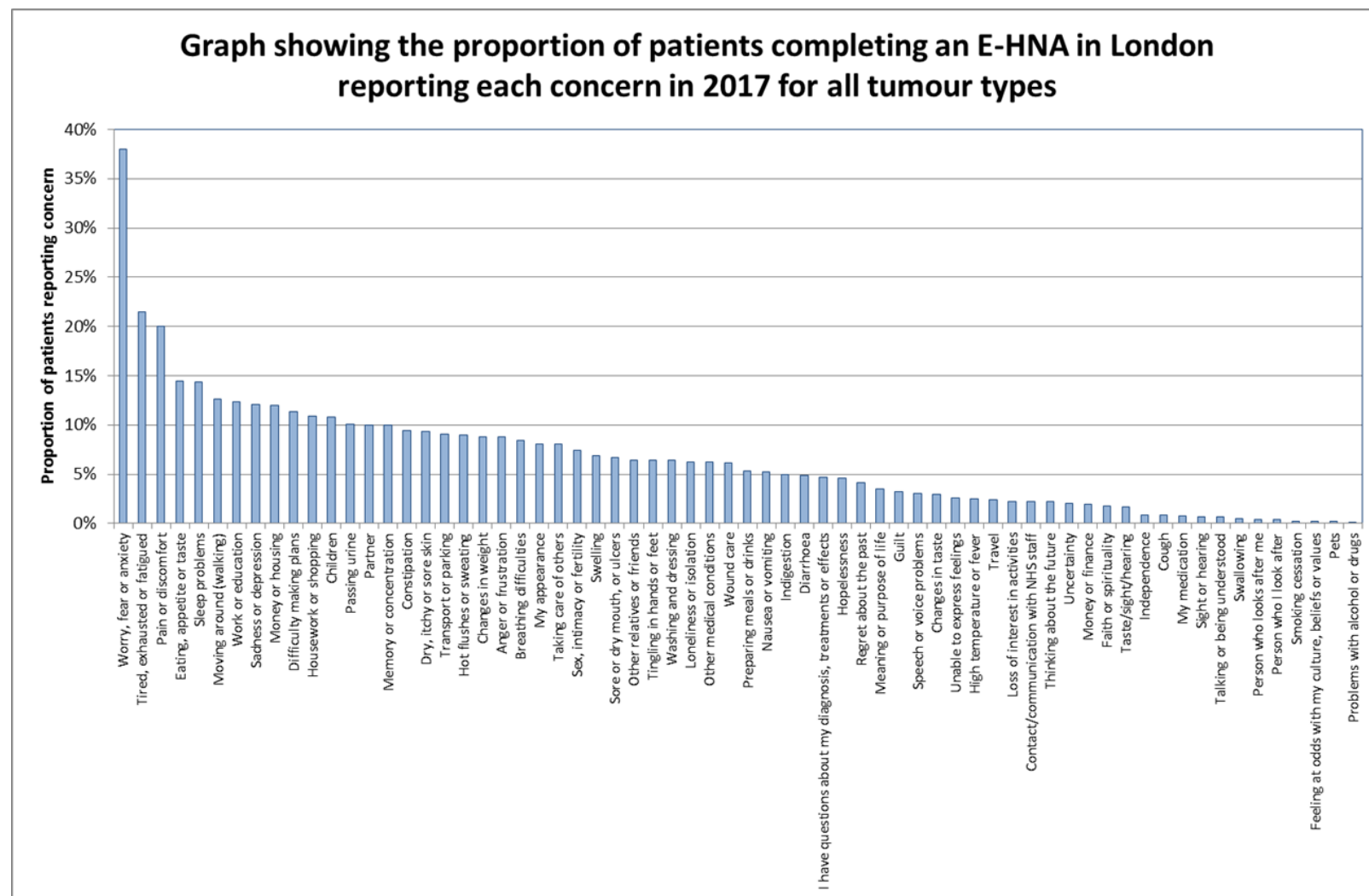
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Appendices

Appendix A: London wide E-HNA audit collated by RM Partners West London Cancer Alliance on behalf of London Cancer Alliances (reproduced with permission)

1. Top concerns - overall



2. Top concerns – by tumour type

2.. Top concerns – by tumour type

Breast

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Worry, fear or anxiety	766	42.6%
Tired, exhausted or fatigued	392	21.8%
Pain or discomfort	341	19.0%
Hot flushes or sweating	319	17.8%
Sleep problems	314	17.5%
Sadness or depression	299	16.6%
Children	275	15.3%
Housework or shopping	273	15.2%
Memory or concentration	268	14.9%
Work or education	263	14.6%

Gynaecology

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Worry, fear or anxiety	701	58.9%
Pain or discomfort	307	25.8%
Tired, exhausted or fatigued	277	23.3%
Moving around (walking)	224	18.8%
Difficulty making plans	199	16.7%
Work or education	196	16.5%
Eating, appetite or taste	178	15.0%
Children	168	14.1%
Swelling	160	13.4%
Housework or shopping	152	12.8%

Haematology

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Worry, fear or anxiety	509	56.9%
Tired, exhausted or fatigued	245	27.4%
Moving around (walking)	237	26.5%
Pain or discomfort	235	26.3%
Work or education	208	23.2%
Partner	188	21.0%
Children	182	20.3%
Dry, itchy or sore skin	174	19.4%
Eating, appetite or taste	172	19.2%
Money or housing	156	17.4%

Head and Neck

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Worry, fear or anxiety	224	42.6%
Eating, appetite or taste	178	33.8%
Pain or discomfort	169	32.1%
Tired, exhausted or fatigued	109	20.7%
Sore or dry mouth, or ulcers	109	20.7%
Sleep problems	91	17.3%
Speech or voice problems	91	17.3%
Money or housing	84	16.0%
Transport or parking	75	14.3%
Wound care	73	13.9%

Lower GI

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Worry, fear or anxiety	90	15.3%
Pain or discomfort	48	8.2%
Tired, exhausted or fatigued	39	6.6%
Sleep problems	37	6.3%
Money or housing	36	6.1%
Constipation	34	5.8%
Diarrhoea	30	5.1%
Work or education	29	4.9%
Children	29	4.9%
Eating, appetite or taste	27	4.6%

Lung

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Worry, fear or anxiety	95	36.3%
Pain or discomfort	89	34.0%
Tired, exhausted or fatigued	89	34.0%
Breathing difficulties	87	33.2%
Eating, appetite or taste	86	32.8%
Money or housing	67	25.6%
Moving around (walking)	66	25.2%
Housework or shopping	63	24.0%
Sleep problems	56	21.4%
Transport or parking	56	21.4%

Skin

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Worry, fear or anxiety	174	48.3%
Wound care	123	34.2%
Dry, itchy or sore skin	45	12.5%
Pain or discomfort	42	11.7%
Other medical conditions	42	11.7%
Moving around (walking)	38	10.6%
Work or education	32	8.9%
Anger or frustration	31	8.6%
Partner	30	8.3%
Other relatives or friends	29	8.1%

Upper GI

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Eating, appetite or taste	205	29.2%
Worry, fear or anxiety	197	28.1%
Pain or discomfort	127	18.1%
Tired, exhausted or fatigued	119	17.0%
Money or housing	73	10.4%
Moving around (walking)	65	9.3%
Children	65	9.3%
Difficulty making plans	65	9.3%
Sadness or depression	60	8.5%
Changes in weight	60	8.5%

Sarcoma

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Worry, fear or anxiety	13	37.1%
Transport or parking	10	28.6%
Tired, exhausted or fatigued	9	25.7%
Moving around (walking)	8	22.9%
Pain or discomfort	7	20.0%
Money or housing	6	17.1%
Work or education	6	17.1%
Housework or shopping	6	17.1%
Other relatives or friends	6	17.1%
Sleep problems	5	14.3%

Tumour type not stated

Concern	Number of e-HNAs	% of patients who had E-HNA with concern
Worry, fear or anxiety	569	35.8%
Tired, exhausted or fatigued	479	30.1%
Sleep problems	384	24.2%
Pain or discomfort	360	22.6%
Memory or concentration	284	17.9%
Changes in weight	278	17.5%
Money or housing	271	17.0%
Sadness or depression	268	16.9%
Eating, appetite or taste	262	16.5%
Moving around (walking)	261	16.4%

3. Concerns with the biggest increase between patients between newly diagnosed and patients at end of treatment - London

Concern	Newly diagnosed (2,783 E-HNAs)		End of treatment (1,501 E-HNAs)		Difference in newly diagnosed and end of treatment
	Number of e-HNAs	% of patients who had E-HNA with concern	Number of e-HNAs	% of patients who had E-HNA with concern	
Hot flushes or sweating	118	4.2%	266	17.7%	13.5%
Tired, exhausted or fatigued	436	15.7%	416	27.7%	12.0%

Tingling in hands or feet	101	3.6%	140	9.3%	5.7%
Sleep problems	311	11.2%	248	16.5%	5.3%
Memory or concentration	188	6.8%	181	12.1%	5.3%
Sex, intimacy or fertility	146	5.2%	156	10.4%	5.1%
Diarrhoea	80	2.9%	108	7.2%	4.3%
Passing urine	263	9.5%	200	13.3%	3.9%
Pain or discomfort	516	18.5%	326	21.7%	3.2%
Dry, itchy or sore skin	209	7.5%	157	10.5%	2.9%

4. Concerns with the biggest decrease between patients between newly diagnosed and patients at end of treatment - London

Concern	Newly diagnosed (2,783 E-HNAs)		End of treatment (1,501 E-HNAs)		Difference in newly diagnosed and end of treatment
	Number of e- HNAs	% of patients who had E-HNA with concern	Number of e- HNAs	% of patients who had E-HNA with concern	
Worry, fear or anxiety	1227	44.1%	433	28.8%	-15.2%

Difficulty making plans	340	12.2%	118	7.9%	-4.4%
Transport or parking	239	8.6%	64	4.3%	-4.3%
Children	330	11.9%	115	7.7%	-4.2%
Partner	286	10.3%	94	6.3%	-4.0%
Taking care of others	252	9.1%	81	5.4%	-3.7%
Eating, appetite or taste	380	13.7%	162	10.8%	-2.9%
Money or housing	306	11.0%	123	8.2%	-2.8%
Wound care	223	8.0%	81	5.4%	-2.6%
Work or education	343	12.3%	149	9.9%	-2.4%

Appendix B: Cancer Rehabilitation Steering Group Members

Role	Organisation	Name
Macmillan Rehabilitation Clinical Lead (Chair)	TCST	Dr Karen Robb
Macmillan Mental Health Clinical Lead	TCST	Dr Philippa Hyman
User representative	Pelvic Radiation Disease Association	David Jillings
Lead for Macmillan Integrated Cancer Programme, Living with and Beyond Cancer and Allied Health Professionals	London Cancer	Sharon Cavanagh
National Cancer Rehabilitation Lead	Macmillan Cancer Support	June Davis
Cancer Commissioning Manager	NEL Commissioning Support Unit	Katherine Kavanagh
Macmillan Nurse Consultant in Colorectal Cancer	St Mark's Hospital	Dr Claire Taylor
Oncology Therapies Lead	Barts Health NHS Trust	Lindsay Farthing
Health and Wellbeing Manager	Havering	Viki Bainsfair
Community Head and Neck Team Lead	Guys and St Thomas NHS Trust	Samantha Tordesillas
Therapy Radiographer/Proton lead	University College London Hospital	Neil Burley
Principal Social Worker	Royal Borough of Kingston	Dawn Secker
Clinical Lead Physiotherapist	Marie Curie Hospice	Karen Turner
Regional Lead AHP	NHS England (London)	tbc
Macmillan Project Manager LWBC	RM Partners	Vanessa Brown
Assistant Director, Clinical Commissioning	Haringey CCG	Rachel Lissauer
Macmillan Social Prescribing Manager	Bromley by Bow Centre	Bianca Karpf
Macmillan Project Manager LWBC	GSTT	Amanda Shewbridge
Clinical Specialist Physiotherapist, Living With and Beyond Cancer/Joint Head of Speech and Language Therapy	Royal Marsden Hospital NHS Trust	Siobhan Cowie-Dickie/Kate Ashforth (sharing role)
Macmillan Project Manager	TCST	Sophie Lansdowne

Appendix C: Cancer Rehabilitation Mapping Task and Finish Group members

Georgina Wiley <i>(project lead Jan – June 2018)</i>	Macmillan Project Facilitator, TCST
Sophie Lansdowne <i>(project lead Nov 2018 – April 2019 and final report author)</i>	Macmillan Project Manager, TCST
Ashley Bowcock	Macmillan Senior Project Support - Living with and beyond Cancer RM Partners
Mary Tsikata	Macmillan Senior Project Support - Living with and beyond Cancer RM Partners
Roxanne Payne	Project Coordinator for Macmillan Integrated Cancer (MiCa) Programme, London Cancer, UCLH Cancer Collaboration

Appendix D: Cancer Rehabilitation Data Task & Finish group

Dr Karen Robb	Macmillan Rehabilitation clinical lead, TCST
June Davis	National cancer rehabilitation lead, Macmillan Cancer Support
Sam Tordesillas	Clinical Team Lead, Community Head and Neck Cancer Team, Lewisham and Greenwich NHS Trust / Guys and St Thomas NHS Trust
Viki Bainsfair	Community Exercise Provider, YMCA
Lindsay Farthing	Oncology Therapies Lead, Barts Health NHS Trust
David Jillings	Service User and Trustee, the Pelvic Radiation Disease Association
Jason Petit	Senior Cancer Intelligence Lead, TCST
Molly Loughran	Cancer Information Analyst, TCST-NCRAS

Appendix E: Service Improvement Tools Task and Finish Group

Dr Karen Robb	Macmillan Rehabilitation clinical lead, TCST
Georgina Wiley (project lead)	Macmillan Project Facilitator, TCST
June Davis	Policy and Impact Specialist Advisory Division AHP Advisor, Macmillan
Karen Turner	Service and Clinical Lead Physiotherapist, Royal Free London NHS Foundation Trust
David Jillings	Service User and Trustee, the Pelvic Radiation Disease Association

Appendix F: Examples of Good Practice Task and Finish Group

Sophie Lansdowne (project lead)	Macmillan Project Manager, TCST
Liz Price	Associate Director, TCST
Kate Ashforth	Joint Head of Speech and Language Therapy, Royal Marsden Hospital NHS Trust
June Davis	Policy and Impact Specialist Advisory Division AHP Advisor, Macmillan
Dr Anna Lowe	AHP Cancer Implementation Manager NHS England
David Jillings	Service User and Trustee, the Pelvic Radiation Disease Association
Doro Bechinger	Service user

Appendix G: Template Survey for service providers (please note: this is written version of the electronic version provided via the online platform, Survey Monkey)



**Healthy London
Partnership**

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

Voluntary

Other (add details)

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

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
Health Care
professional
Other

Invitation by health
care professional
Either Self Refer or
HCP

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 H: Template Survey for commissioners (please note: this is written version of the electronic version provided via the online platform, Survey Monkey)

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	Voluntary and third sector
Other (add details)	Local Authority

7. Summary of service

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

Community	Primary care
Secondary care inpatient	Secondary care outpatient
Tertiary/specialist inpatient	Tertiary/specialist outpatient
Home	Other (add details)

Hospice	Yes/No
Other	

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!

Appendix I: Proposed cancer rehab minimum dataset as agreed by task and finish group

Question Group	Question
Demographic	<ul style="list-style-type: none"> • Age • Sex • Ethnicity
Cancer History	<ul style="list-style-type: none"> • Cancer type • Date of diagnosis • Cancer treatment • Stage of treatment
Provider	<ul style="list-style-type: none"> • Date form completed • Name of provider • Provider type • Setting • Provider profession
Therapy	<ul style="list-style-type: none"> • Date of referral and referrer • Reason for rehabilitation • Treatment received • Details of any other non-cancer related rehab for another issue? • Number of visits - one to one and group • Discharge Status

Some additional items will not be recommended for inclusion in the initial implementation and pilot phase, but should be recorded and considered for inclusion in future versions of the dataset. Their value and reasoning for exclusion from phase 1 of the dataset implementation is outlined in Table 4.2.

Table 4.1 Items not recommended for collection in phase 1 but identified as items valuable to collect

Item	Reason for not collecting
NHS Number	NHS number is identified as a valuable data item in order to link to other datasets and additional demographic information and follow patients across various providers. However, it would delay implementation of dataset to resolve IG issues around collection and storage of data. Additionally, as identified in the interview process, some community providers do not collect NHS number.
Patient Reported Outcome Measure	PROMs provide valuable insight into the outcome of the rehabilitation intervention, but they are time consuming to collect and often collected inconsistently. The coming NHSE Quality of Life metric (due Feb 2019) will provide similar data but is not yet released and requires NHS number for linking.

SNOMED codes for reported symptoms and treatments given

While SNOMED codes allow for standardised definitions of clinical terms, their collection is not currently required and would require additional clinical time to code correctly. Recognising that these codes could be required for collection in the future, this data item should be included in the dataset if that change occurs.

Comorbidity

While data on comorbidity among patients diagnosed with cancer remains a priority, it is difficult to define and collect consistently using a single comorbidity measure pan-London. Recognising these difficulties, collecting comorbidity information should be delayed to later phases of the dataset.

Appendix J: Proposed cancer rehabilitation dataset with definitions

Question group	Question no.	Question	Response options
Demographic	1	Age	(free text)
	2	Sex ⁷³	male female unspecified or other
	3	Ethnicity ⁷⁴	Asian or Asian British - Indian Asian or Asian British - Pakistani Asian or Asian British - Bangladeshi Asian or Asian British - Any other Asian background Black or Black British - Caribbean Black or Black British - African Black or Black British - Any other Black background Chinese White - British White - Irish White - Any other White background Mixed - White and Black Caribbean Mixed - White and Black African Mixed - White and Asian Mixed - Any other mixed background Any other ethnic group Not stated

⁷³ Sex category is intended as biological sex, however for those who do not wish to identify as male or female, gender identity guidance is still under review by ONS <https://www.ons.gov.uk/methodology/classificationsandstandards/measuringequality/genderidentity>. The current option of unspecified is advised by gov.uk service manual <https://www.gov.uk/service-manual/design/gender-or-sex>

⁷⁴ Categories derived from NHS data dictionary http://www.datadictionary.nhs.uk/data_dictionary/attributes/e/end/ethnic_category_code_de.asp

Question group	Question no.	Question	Response options
Cancer	4	Cancer type ⁷⁵	Cancers of the Brain and Central Nervous System (CNS) Breast Cancer Children's Cancer Gynaecological Cancers Haematological Cancers Head and Neck Cancers (incl. thyroid cancer) Lower-Gastrointestinal Cancers - LGI (colon, rectal, anal) Lung Cancers Sarcoma Skin Cancers Upper Gastrointestinal Cancer (oesophageal, stomach, pancreatic, liver) Urological Cancers (bladder, prostate, renal, testicular, upper tract transitional cell) Other (free text)
	5	Date of diagnosis	(free text date format)
	6	Cancer treatment ^{17,76}	Anti-Cancer Drug Regimen (Chemotherapy) Palliative Care and Active Monitoring Radiotherapy Surgery Other (free text)
	7	Stage of treatment	Diagnosis and Care Planning Treatment Post treatment Palliative care

⁷⁵ Definitions derived from National Cancer Waiting Times Monitoring Dataset Guidance https://digital.nhs.uk/media/896/National-Cancer-Waiting-Times-Monitoring-Dataset-Guidance/pdf/National_Cancer_Waiting_Times_Monitoring_Dataset_Guidance

⁷⁶ Multiple selections will be allowed i.e. participants can select as many options as needed.

Question group	Question no.	Question	Response options
Provider	8	Date form completed	(free text date format)
	9	Name of provider organisation or trust	select from list
	10	Provider type	NHS Private Voluntary/Third Sector Local Authority Other (free text)
	11	Setting	Community Primary care Secondary Tertiary/specialist Home Other (free text)
	12	Provider profession ⁷⁷	Art Therapist Drama Therapist Music Therapist Podiatrist Dietitian Occupational Therapist Prosthetists and Orthotist Paramedic Physiotherapist Diagnostic Radiographer Therapeutic Radiographer Speech and Language Therapist Other (free text)

⁷⁷ Derived from Allied Health Professions into Action, NHS England <https://www.england.nhs.uk/ourwork/qual-clin-lead/ahp/>

Question group	Question no.	Question	Response options
Therapy	13	Date of referral	(free text date format)
	14	Referring provider	(free text field)
	15	Reason for rehabilitation ^{78,79,80}	Physical or Movement - Respiratory Problems Physical or Movement - Musculoskeletal Problems Physical or Movement - Gastrointestinal Problems Physical or Movement - Neurological Problems Physical or Movement – Dietary, H&N, Swallowing Physical or Movement – Urinary Sensory Problems Cognitive or Behavioural Problems Communication Problems Psychological and Emotional Problems Medically Unexplained Symptoms Mental Health Conditions Practical Concerns and Everyday Activity Problems Other (free text)

⁷⁸ Adapted from the Commissioning Guidance for Rehabilitation <https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf> (pg. 7) and NCAT rehabilitation pathway work.

⁷⁹ Multiple selections will be allowed i.e. participants can select as many options as needed.

⁸⁰ It should be included in the instructions that when the service provider is unsure how to categorise the rehabilitation reason, they can select other and write a fitting description. This will aid during the pilot to determine which category choices should be added or amended

Question group	Question no.	Question	Response options
Therapy (continued)	16	Treatment received ⁸¹	Advising on self-management Healthy lifestyle patient groups Making referrals to other healthcare professionals Signposting patients to other healthcare providers, sectors or settings Supporting those with commonly presenting side effects and rehabilitation needs Delivering interventions that require knowledge and experience of the effects of cancer treatment Delivering specialist interventions for patients having radical surgery or combinations of treatments Delivering specialist interventions for patients with advanced diseases, complex palliative and end of life care issues Delivering specialist interventions to patients with severe functional and cognitive impairment Delivering specialist interventions to patients with severe functional and cognitive impairment Supporting families of carers of your patients Other (free text)
	17	Receiving non-cancer related rehabilitation for another issue? ⁸²	Yes No Unknown
	18	Number of visits-one to one	(free text)
	19	Number of visits-group	(free text)
	20	Discharge Status - Treatment complete?	Yes No
	21	Discharge Status - Onward referral? ²⁴	Yes (add detail as free text) No

⁸¹ It should be included in the instructions that when the service provider is unsure how to categorise the treatment, they can select other and write a fitting description. This will aid during the pilot to determine which category choices should be added or amended

⁸² It needs to be decided if a free text field is allowed to capture additional information. The risk with free text fields is that they require additional analysis to capture meaning in the data.

Appendix K: Minimum Data set pilot proforma



**Healthy London
Partnership**



Transforming Cancer Services Team

DATE FORM COMPLETED:

NAME OF PROVIDER/ORANISATION:

Notes: Please complete one form for every patient you have discharged. Please circle the answer that best applies. For Sections 7, 10, 14, 15, 16: circle as many boxes as that apply. Further details can be found in the accompanying guide.

1. Age (yrs): _____

2. Sex: **M** **F** **other**

3. Borough: _____

4. Ethnicity (please circle)

Asian or Asian British – Indian

Asian or Asian British – Bangladeshi

Black or Black British – Caribbean

Black or Black British – any other black background

White - British

White – any other white background

Mixed – White and Black African

Mixed – any other mixed background

Not stated

Asian or Asian British – Pakistani

Asian or Asian British- any other Asian background

Black or Black British – African

Chinese

White - Irish

Mixed – White and Black Caribbean

Mixed – White and Asian

Any other ethnic group

5. Cancer type (please circle)

Cancers of the brain and central nervous system

Children's cancer

Haematological cancer

Lower gastrointestinal cancer (GI) (colon, rectal, anal)

Sarcoma

Upper gastrointestinal cancer (oesophageal, stomach, pancreas, liver)

Other (add details)

Breast cancer

Gynaecological cancer

Head and neck cancer (inc. thyroid)

Lung cancer

Skin cancer

Urological cancer (bladder, prostate, renal.

Testicular, upper tract transitional cell)

6. Month and year of diagnosis _____

7. Cancer treatment (please circle all that apply)*Anti-cancer drug regime (chemo)**Radiotherapy**Other:**Palliative care and active monitoring**Surgery***8. Intent/stage of treatment (please circle):***Diagnosis and care planning**Treatment**Post treatment**Palliative care***9. Provider type (please circle)***NHS**Private**Voluntary**Local authority**Other (add details)***10. Setting (please circle all that apply):***Community**Secondary care inpatient**Tertiary/specialist inpatient**Home**Primary care**Secondary care outpatient**Tertiary/specialist outpatient**Other (add details)***11. Provider profession (please circle)***Art therapist**Music therapist**Dietitian**Prosthetists and Orthotists**Physiotherapist**Therapeutic radiographer**Social prescriber**Other (add details)**Drama therapist**Podiatrist**Occupational therapist**Paramedic**Diagnostic radiographer**Speech and language therapist**Physical activity***12. Date of referral** _____**13. Referrer (type and setting)** _____**14. Reason for referral (please circle all that apply)***Physical or movement – respiratory problems**Physical/movement – gastrointestinal**Physical/movement – dietary, head & neck, swallowing**Sensory problems**Communication problems**Medically unexplained symptoms**Practical concerns and everyday activity problems**Physical/movement – musculoskeletal**Physical/movement – neurological**Physical/movement – urinary**Cognitive/behavioural problems**Psychological/emotional problems**Mental health conditions**Other (add details)*

15. Identified needs (please circle all that apply)

Physical or movement – respiratory problems	Physical/movement – musculoskeletal
Physical/movement – gastrointestinal	Physical/movement – neurological
Physical/movement – dietary, head & neck, swallowing	Physical/movement – urinary
Sensory problems	Cognitive/behavioural problems
Communication problems	Psychological/emotional problems
Medically unexplained symptoms	Mental health conditions
Practical concerns and everyday activity problems	Other (add details)

16. Treatment received (please circle all that apply)

Advising on self-management	Healthy lifestyle patient groups
Making referrals to other health professionals	Signposting patients to other healthcare providers, sectors or settings
Supporting those with commonly presenting side effects and rehab needs	Delivering interventions that require knowledge and experience of the effects of cancer treatment
Delivering specialist interventions for patients having radical surgery/combination of treatment	Delivering specialist interventions for patients with advanced disease, complex palliative /end of life issues
Delivering specialist interventions to patients with severe functional and cognitive impairment	Supporting families of carers of your patients
Other (add details)	

17. Receiving non cancer related rehabilitation for another issue: Yes No Unknown

18. Number of visits (1-2-1) by patient to person completing the form _____

19. Number of visits (in group setting) by patient to person completing the form: _____

20. Date of discharge: _____

21a. Discharge status: rehabilitation treatment complete? Yes No

21b. Discharge status: onward referral? Yes No

(If yes) details: _____

(If no) details: _____

Appendix L: Minimum Dataset proforma – How to guide



**Healthy London
Partnership**



Transforming Cancer Services Team

Minimum Dataset – Crib Sheet

The following information should be used to complete the *Minimum Dataset proforma form*.

Key Dates

Pilot sites to provide retrospective September data to TCST (paper based)	November 17 th 2017
Conference call to discuss learnings and modifications needed	November 23 rd 2017 (09.30-10.30)
Pilot sites to provide prospective Nov/Dec data to TCST (paper based). Leads to involve colleagues as able.	December 8 th 2017
Second conference call	December 13 th 2017(09.45-10.45)
Pilot sites to continue collecting 'real time data' but move to excel based collection.	January 8 th 2018
Additional pilot sites come on board	Feb/March 2018
Showcase/Engagement event	April 2018 tbc

Tips for filling in the forms:

- Please complete one form for every patient you have discharged. A separate form should be completed for each provider (this may mean that more than one form is filled out for each patient) i.e. if you are part of an MDT and several of your colleagues are also seeing the patient, only complete the form for your activity with the patient.
- If more than one answer applies please circle all relevant answers
- If no provided answer fits with your response please provide as much detail as possible in the 'other' section. This will help us refine our form at a later stage.
- Please keep a log of any feedback that you may have on this process as you go along to report back to the group. You may like to use the log below to do this.

Instructions for individual questions:

- Question 3: **Borough**. Please consider the following when answering this question:
 - Where does the patient pay council tax?
 - If this is not clear: what physical location does the patient reside in?
- Question 8: **Intent/stage of treatment**. Please consider this question from your own knowledge of the patient
- Question 12: **Referrer**: Please document type of professional referring and setting if necessary e.g. GP, community physiotherapist, self-referral.
- Question 16: **Receiving non cancer related rehabilitation for another issue**: Please document any other rehabilitation the patient is receiving beyond the care you are providing e.g. receiving outpatient physiotherapy for a sports injury.
- Questions 17/18: **Number of visits (1-2-1 and in groups)**: Please document number of contacts made with patient, whether as a 1-2-1 or as a group contact. Please record all contacts whether face to face, over the phone or other.
- Question 20a: **Discharge status: rehabilitation treatment complete?** This relates to whether the rehabilitation you are providing is completed at point of discharge, or whether more treatment is required. If the latter applies please record 'N'.
- Question 20b: **Discharge status: onward referral?** This relates to whether the patient has been referred to another provider. If you record 'Y' please provide additional details of where you have referred to, e.g. community exercise group or psychological support services. If you record 'N' please record the reason why e.g. patient deceased or no services to refer to.

If you have any urgent questions or concerns about filling in this form please contact Karen Robb Karen.rob3@nhs.net or Georgina Wiley Georgina.Wiley@nhs.net

Feedback Log**Feedback****Possible solution**

Appendix M: E-HNA Survey Questions for Patient with suggested drop down list

9. What rehabilitation needs are you getting support for?

Problems with eating and drinking

Weight loss

Breathlessness

Weakness

Reduced range of movement/joint stiffness

Problems with communication

Swallowing problems

Incontinence (bladder and/or bowel)

Fatigue

Lymphoedema/chronic swelling

Problems with mobilising/getting around

Pain

Psychological/emotional problems

Memory and concentration

Support with practical tasks e.g. dressing

Other

10. Do you have any other rehabilitation needs you are not receiving support for?

Problems with eating and drinking

Weight loss

Breathlessness

Weakness

Reduced range of movement/joint stiffness

Problems with communication

Swallowing problems

Incontinence (bladder and/or bowel)

Fatigue

Lymphoedema/chronic swelling

Problems with mobilising/getting around

Pain

Psychological/emotional problems

Memory and concentration

Support with practical tasks e.g. dressing

Other

11. Who were you referred to for support with the above?

Art therapist

Drama therapist

Music therapist

Podiatrist

Dietitian

Occupational therapist

Prosthetist/Orthotist

Physiotherapist

Speech and language therapist

Radiographer

Fitness professional

Support worker

GP

Nurse

Consultant

Clinical Psychologist

Other

Don't know

12. What treatment/advice/support did you receive?

I had one or more 1-2-1 sessions with a healthcare professional

I attended a patient group

I received information and advice on my condition

I am receiving palliative care and am supported with my symptoms

I was referred to another health or care professional

I was signposted to another setting where I could get help e.g. local gym

I found myself help e.g. online

5. In what setting did you receive your rehabilitation?

Community clinic

Leisure centre

GP surgery

Hospital (in-patient)

Hospital (out-patient)

My home

Residential or nursing home

Other

6. How effective was the rehabilitation you received? Please give a total score for all of it.

Insert 0-10 scale

7. Do you need onward referral for further treatment/advice/support?

Yes

No

Don't know

8. Have you got an onward referral for further treatment/advice/support?

Yes

No

Don't know

9. If so where is this referral to?

Art therapist

Drama therapist

Music therapist

Podiatrist

Dietitian

Occupational therapist

Prosthetist/Orthotist

Physiotherapist

Speech and language therapist

Therapeutic radiographer

Fitness professional

Support worker

GP

Nurse

Consultant

Clinical Psychologist

Other

Don't know

Appendix N: Dataset in format compatible with NHS Digital systems

Data Item No.	Data Item Section	Data Item Name	Data Item Description	Format	Code	Code Definition	Comparable NHS Data Dictionary Element	Other collections	Schema Specification*	SHORT FORM DATASET
RHB001	PATIENT IDENTITY DETAILS	NHS NUMBER*	*For linkage purposes NHS NUMBER and/or LOCAL PATIENT IDENTIFIER is required. The NHS NUMBER, the primary identifier of a PERSON, is a unique identifier for a PATIENT within the NHS in England and Wales. This will not vary by any ORGANISATION of which a PERSON is a PATIENT.	n10			NHS NUMBER		Mandatory	y
RHB004	DEMOGRAPHICS	POSTCODE OF USUAL ADDRESS (AT DIAGNOSIS)	POSTCODE OF USUAL ADDRESS (AT DIAGNOSIS) is the POSTCODE OF USUAL ADDRESS of the PATIENT at the time of PATIENT DIAGNOSIS.	max an8			POSTCODE OF USUAL ADDRESS (AT DIAGNOSIS)	ONS	Required	y
RHB011	REHAB TEAM DETAILS	REHAB SETTING TYPE	The setting in which this course of rehab is provided	an2	01 02 03 04 05 06 07 98	Community Primary Care Secondary Care (Inpatient) Secondary Care (Outpatient) Tertiary/Specialist (Inpatient) Tertiary/Specialist (Outpatient) Home Other			Required	y
RHB012	REHAB TEAM DETAILS	REHAB PROVIDER PROFESSION	The profession of the rehab provider for this rehab treatment type	an2	01 02 03 04 05 06 07 08 09 10 11 12 13 14 15 98	Art therapist Drama therapist Music therapist Podiatrist Dietitian Occupational therapist Prosthetists and Orthotists Paramedic Physiotherapist Diagnostic radiographer Therapeutic radiographer Speech and language therapist Social prescriber Physical activity Psychologist / Mental Health Support Other			Required	y
RHB017	REHAB INTERVENTION DETAILS	IDENTIFIED REHAB NEEDS	Rehab needs identified by rehab team after referral	an2	01 02 03 04 05 06 07 08 09 10 11 12 13 98	Physical or movement – respiratory problems Physical/movement – musculoskeletal Physical/movement – gastrointestinal Physical/movement – neurological Physical/movement – dietary, head & neck, swallowing Physical/movement – urinary Sensory problems Cognitive/behavioural problems Communication problems Psychological/emotional problems Medically unexplained symptoms Mental health conditions Practical concerns and everyday activity problems Other			Required	y
RHB018	REHAB INTERVENTION DETAILS	TREATMENT RECEIVED	Rehab treatment received	an2	01 02 03 04 05 06 07 08 09 10 11 98	Advising on self-management Healthy lifestyle patient groups Making referrals to other health professionals Signposting patients to other healthcare providers, sectors or settings Supporting those with commonly presenting side effects and rehab needs Delivering interventions that require knowledge and experience of the effects of cancer treatment Delivering specialist interventions for patients having radical surgery/combination of treatment Delivering specialist interventions for patients with advanced disease, complex palliative/end of life issues Delivering specialist interventions to patients with severe functional and cognitive impairment Supporting families of carers of your patients Providing psychological interventions to individuals, families, carers or teams Other			Required	y
RHB020	REHAB INTERVENTION DETAILS	NUMBER OF VISITS (1-2-1) BY PATIENT TO REHAB PROVIDER	Number of 1-2-1 visits by patient in relation to this rehab course	n3					Required	y
RHB021	REHAB INTERVENTION DETAILS	NUMBER OF VISITS (GROUP SETTING) BY PATIENT TO REHAB PROVIDER	Number of visits by patient to group settings in relation to this rehab course	n3					Required	y
RHB024	REHAB OUTCOME	ONWARD REFERRAL	Onward referral for further treatment	an2	01 02 03	Yes No Unknown			Required	y
RHB024A	REHAB OUTCOME	ONWARD REFERRAL DETAIL	Further details on onward referral	AN60					Required	y
Total Individual Questions (Including patient identifiers):					10					
Total Individual Questions (Excluding patient identifiers):					8					