

# Cancer rehabilitation services – Data recommendation report

Transforming Cancer Services Team

October 2017

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## Who we are, what we do

The Transforming Cancer Services programme was established in April 2014 to provide strategic leadership, clinical advice, oversight, cohesion and guidance for implementing the Five Year Cancer Commissioning Strategy for London. We aim to improve outcomes for patients through a pan-London clinically led, patient-centred collaborative approach.

The Transforming Cancer Services programme is part of the Healthy London Partnership. The Healthy London Partnership brings together London's health and care system to deliver changes that are best done "once for London".

### Workstreams in our programme include:

- Earlier detection and awareness
- Cancer waits and diagnostics
- Living with and beyond cancer
- Support commissioning and contracting
- Improving patient experience

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

Our **mission** is as a trusted partner, 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 national strategy
- 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

## Executive Summary

This purpose of this report is to present findings from a detailed investigation of cancer rehabilitation data available pan-London and make recommendations for data collection and collation at a pan-London level to support commissioners and other cancer rehabilitation stakeholders.

Investigation methodology included the following:

- Scoping work to identify if substantial cancer rehabilitation data existed in known cancer registry datasets
- Planning sessions to identify other sources of cancer rehabilitation data
- Targeted interviews to extract information from sources identified in the planning session and interpretation of interview findings
- Formation of a task and finish group to make recommendations for dataset
- Development of a proposed minimum dataset for cancer rehabilitation

The findings of the scoping work, interviews and task and finish group indicated that a new dataset should be developed for cancer rehabilitation services in London. Specific recommendations for the dataset were drawn from interview key themes:

- Challenges and complexities with current data collection
- Demonstrating impact and value of cancer rehabilitation
- Linking with strategic priorities and existing workstreams
- Learning from established datasets for a phased approach to implementation
- Represent the full spectrum of rehabilitation services.

The proposed minimum dataset for cancer rehabilitation recommends 17 measures to be collected falling under four broad categories:

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

Implementation of the dataset should use a phased approach which involves piloting the dataset, performing an audit, and iteratively revising and adding data items to the dataset.

## Acknowledgements

The author of this report would like to thank the following for their time and valuable input into the project design, report structure and content:

- Karen Robb, Liz Price, and Lucy Young for their project supervision.
- Interviewees Sam Tordesillas, Lindsay Farthing, Sarah Bengner, David Jillings, Jason Petit, Andrew Nwosu, and Joanne Fillingham.
- Task and finish group members June Davis, Sam Tordesillas, Viki Bainsfair, David Jillings, and Jason Petit.
- The service users whose data could contribute to improvement of cancer rehabilitation services in London.
- The TCST Cancer Rehabilitation Steering Committee members for their advisory role.

## Introduction

The purpose of this report is to present findings from a detailed investigation of cancer rehabilitation data available pan-London and make recommendations for data collection and collation at a pan-London level. It is specifically targeted at commissioners and rehabilitation service providers, but also to all stakeholders with an interest in cancer rehabilitation, including service users, the voluntary sector and others across the spectrum of health and social care.

Molly Loughran (ML), working as a partnership Cancer Information Analyst with Transforming Cancer Services Team (TCST) and the National Cancer Registration and Analysis Service (NCRAS), led this work and authored this report and her post was fully funded by TCST. Dr Karen Robb (KR), Macmillan Rehabilitation Clinical Lead for TCST, supervised the project and oversees the TCST Cancer Rehabilitation workstream. Project support came from TCST's Living With and Beyond Cancer (LWBC) team, with Liz Price, Associate Director (LWBC), providing additional advisory support.

This report contains four sections:

1. Background and strategic context
2. Methodology and summary of research activities
3. Findings from scoping work and stakeholder interviews
4. Recommendations and next steps

## 1 Background and Strategic Context

### 1.1 An overview of need for cancer rehabilitation data in London

Cancer is highlighted as a national priority with the Achieving World-Class Cancer Outcomes strategy for England<sup>1</sup>, published July 2015, emphasizing the Recovery Package and stratified follow up pathways. The more recent commissioning guidance from NHS England<sup>2</sup> supports access to these strategic priorities. Previous work by the Transforming Cancer Services Team (TCST) and NHS England has shown that pan-London data on people who have a cancer diagnosis and have been offered or have had cancer rehabilitation services 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.

TCST's *Cancer rehabilitation: a scoping report for London*<sup>3</sup>, published February 2017, has highlighted the need for better cancer rehabilitation data in London. While some services in London are collecting high quality data, the scoping report concludes that:

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<sup>1</sup> Achieving world-class cancer outcomes: a strategy for England 2015-2020. Available at: [http://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<sup>2</sup> Implementing the Cancer Taskforce Recommendations: Commissioning person centred care for people affected by cancer. Available at: <https://www.england.nhs.uk/wp-content/uploads/2016/04/cancer-guid-v1.pdf>

<sup>3</sup> <https://www.healthylondon.org/sites/default/files/Cancer%20rehabilitation%20-%20a%20scoping%20report%20for%20london.pdf>

‘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)

Key recommendations from that report included a focus on data and metrics to improve evaluation, and a clear economic argument for why rehabilitation is important and should be better commissioned. The work plan laid out in the report paves the way for this current data scoping work by calling for mapping the level of need across London CCGs and third sector services.

A previous report by NHS England, *Improving Rehabilitation Services Programme Regional Report – London*<sup>4</sup>, published March 2015, last updated August 2016, identified issues with data, specifically that of Clinical Commissioning Groups (CCGs). The issues highlighted in that report focus on a lack of available data and serve as the impetus for this current work.

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

The regional 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:

‘It is clear that a strategic decision needs to be made about how best to develop better data systems and the ‘big data’ on rehabilitation which is needed to drive improvement in outcomes for patients.’ (pg. 27)

‘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 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.

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<sup>4</sup> NHS England Improving Rehabilitation Services Programme – Regional Report  
<https://www.england.nhs.uk/london/our-work/improving-rehabilitation-services/>



## 1.2 Overview of nationally held cancer datasets and non-cancer rehabilitation datasets

This section provides a review of nationally held datasets which are related to either cancer or rehabilitation and gives an overview of what is held in these datasets. It is clear that there is no nationally held dataset that consistently collects cancer rehabilitation data so the recommendation of this report is to create a dataset that will meet stakeholder needs as outlined in Section 1.3.

### *Cancer Registry and Hospital Episode Statistics*

Public Health England (PHE)'s National Cancer Registration and Analysis Service (NCRAS) holds cancer registry data—including the Cancer Outcomes and Services Dataset (COSD)<sup>5</sup> and Hospital Episode Statistics (HES)<sup>6</sup> data for those with cancer. Details held in the cancer registry include demographic data on patients, information on the tumour(s) of patients, information on some of their treatments and mortality data. HES contains data for each hospital episode at an NHS trust in an inpatient, outpatient, or A&E setting including some diagnosis, and procedure data. It does not necessarily contain data on episodes at a GP or community health centre.

### *National Cancer Waiting Times Monitoring Dataset*

The National Cancer Waiting Times Monitoring Dataset (cancer waits)<sup>7</sup> is a dataset collected by NHS England which includes activity and treatment for those with suspected cancer. However, the dataset excludes rehabilitation in treatment data it collects as it specifically states that subsequent treatment standards do not cover follow on treatments that are not directly related to shrinking or delaying growth/spread of the cancer.<sup>8</sup>

### *UK Rehabilitation Outcomes Collaborative (UKROC)*

UK Rehabilitation Outcomes Collaborative (UKROC)<sup>9</sup> is a robust UK-wide neuro rehabilitation outcomes dataset. It collects demographic data, referral data, main diagnosis, care needed, and outcomes data including changes made during programme and where the patient was discharged to (e.g. home, care home, etc.). The dataset focuses on inpatient data only and does not collect data on continuing care in the community. Nonetheless, the data collected by UKROC is valuable to show what can be collected in a rehabilitation dataset and is a leading example of a dataset to inform commissioning.<sup>10</sup>

### *The Trauma Audit and Research Network (TARN)*

The Trauma Audit and Research Network (TARN) is a robust set of data collected for those with traumatic injuries. It is an in-depth set of datasets which collect detailed care-level information from demographics, injury severity, critical care data, imaging data, etc. and specifically to rehabilitation the dataset collects data on the presence and of a rehabilitation prescription, as

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<sup>5</sup> For more information on COSD see [http://www.ncin.org.uk/collecting\\_and\\_using\\_data/data\\_collection/cosd](http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd)

<sup>6</sup> For more information on HES see <http://content.digital.nhs.uk/hes>

<sup>7</sup> For more information on Cancer Waiting Times see <https://digital.nhs.uk/cancer-waiting-times>

<sup>8</sup> Guidelines for what is collected in the Cancer Waiting Times dataset see the guidance [https://digital.nhs.uk/media/919/Monitoring-Dataset-guidance-changes-from-v8-0-to-v9-0/pdf/Monitoring\\_Dataset\\_guidance\\_-\\_changes\\_from\\_v8-0\\_to\\_v9-0](https://digital.nhs.uk/media/919/Monitoring-Dataset-guidance-changes-from-v8-0-to-v9-0/pdf/Monitoring_Dataset_guidance_-_changes_from_v8-0_to_v9-0)

<sup>9</sup> For more information on UKROC see <http://www.ukroc.org/>

<sup>10</sup> Cancer rehabilitation: a scoping report for London <https://www.healthylondon.org/sites/default/files/Cancer%20rehabilitation%20-%20a%20scoping%20report%20for%20london.pdf>

well as fields pertaining to rehabilitation needs, level of rehabilitation required, recommended and delivery rehabilitation centre and service, rehabilitation delivered, and dates of referral and review. While this dataset is not cancer related, it can provide lessons on data collection, measures collected, and guidance documentation.<sup>11</sup>

### 1.3 Objectives

The overall aim of this report is to present both investigative qualitative analysis of cancer rehabilitation data availability and systems, and exploratory scoping analysis of cancer rehabilitation data in London to inform future work developing comprehensive commissioning guidance.

The results of this exploratory analysis will establish recommendations to identify and assemble data into a pan-London dataset that is available to:

- a.** Support and make recommendations to London commissioners to commission cancer rehabilitation services (acute and community)
- b.** Demonstrate the impact of cancer rehabilitation services
- c.** Determine workforce capacity and need.

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<sup>11</sup> For more information on TARN see <https://www.tarn.ac.uk/Home.aspx>

## 2 Methodology

### 2.1 Overview

Work on this report and scoping work has been carried out under the remit of TCST in partnership with NCRAS. Investigation work was carried out by Molly Loughran, Cancer Information Analyst on a TCST-PHE partnership and lead on the data scoping project. The project was supervised by Dr Karen Robb (KR), Macmillan Rehabilitation Clinical Lead who leads the TCST rehabilitation workstream. Support was provided from a task and finish group (see Appendix A for full membership list). Results were reported back into the Cancer Rehabilitation Steering Committee and pan-London Cancer Intelligence Steering Group. Data scoping work, thought-sharing sessions, stakeholder interviews, and the development of a task and finish group and generation of a proposed minimum cancer rehabilitation dataset were all undertaken over the course of the project.

### 2.2 Methods

#### *a. PHE scoping work undertaken 2016*

In 2016, scoping work was performed of the datasets available to PHE's NCRAS which includes cancer registry data, and HES data. The aim was to identify HES records that indicated rehabilitation services through analysing ICD-10 diagnosis codes, provider specialties, and procedure codes. Codes were identified through a process described in Section 3.1. A list of procedure codes identified to try to further identify patients who had rehabilitation services is included in Appendix B.

#### *b. Planning session*

TCST's LWBC workstream team undertook a half day planning and thought-sharing session to determine possible sources and ways to gather rehabilitation data. The initial results included a definition of the aims for the data project, potential data sources, and a prioritisation of sources to follow up. Some ideas identified for further follow up included targeted interview or peer review with service providers who are known to have existing datasets, examining treatment summaries, READ codes, and patient reported outcome measures (PROMs). These results can be found in Appendix C.

#### *c. Refining process*

Each item from the session was reviewed over three meetings for feasibility by a small working group of the TCST LWBC work stream, including Molly Loughran and Dr Karen Robb, joined intermittently by Jason Petit, Senior Cancer Intelligence Lead, TCST, and Sarita Yaganti Cancer Strategy Implementation Lead, TCST. Several methods were considered, but there was a decision to proceed with targeted interviews of service providers and the interviews were then expanded to include a range of rehabilitation stakeholders. From those interviews, other possible sources of data could be evaluated for availability.

#### *d. Interviews*

To gain greater insight into the areas discussed in the planning session, interviews were carried out with targeted experts in those areas. Interviews took place during May to August 2017 by the author. Interviews were conducted either in person or over the phone and generally lasted 30 minutes. Two one hour in-depth interviews with rehabilitation provider leads occurred early in the

interview process and were used to generate a greater understanding of cancer rehabilitation in general, as well as an overview of data collection in this speciality area.

Further interviews were carried out across a spectrum of stakeholders, including: a community exercise program provider, London Allied Health Professional (AHP) lead, a service user, an NHS England senior programme manager, and the senior cancer intelligence lead for TCST. A full list of those interviewed is available in Appendix D. Interview field notes were recorded electronically at the time of the interview, subsequently reviewed for clarity and kept for further review. Notes were reviewed with working group and key themes were extracted, as detailed in Section 3.3. These findings informed the work of the task and finish group.

#### ***e. Task and finish group***

Following the first round of interviews, a cancer rehabilitation data task and finish group was established. As the findings of the interviews indicated that creating a minimum dataset for cancer rehabilitation should be the recommendation of this report, the group met to clarify what the dataset could achieve, and what data should be collected. The group met three times from July-August 2017, see Appendix A for membership list. The primary outcome of the task and finish group was the agreed minimum dataset shown in Table 4.1.

#### ***f. Report publication and sign off***

The report and recommended dataset were circulated for rounds of feedback and presentation for endorsement at the Pan-London Cancer Rehab Steering Committee, and the Pan-London LWBC Partnership Board. It was also presented to the Pan-London Cancer Intelligence Operational Group.

## 3 Results

The data scoping, interview findings, and steps leading to the recommendations are laid out in this section.

### 3.1 PHE data scoping findings

HES records were analysed for presence of rehabilitation-related codes. No existing lists of OPCS-4 codes related to rehabilitation were known to the team. To form a list, a search of the codes was carried out and all OPCS-4 detailed code descriptions were examined for the word “rehabilitation” and “rehab” and 33 codes were returned (Appendix B). No codes were found containing related words such as “diet”, “exercise”, or “physiotherapy”. Both outpatient and inpatient HES records were examined. HES episodes for the year 2014 were looked at, limiting the scope to those records belonging to cancer patients diagnosed in financial years 2012/13-2014/15. There were only 381 records in the inpatient setting, and 404 records from an outpatient setting. A&E HES records were not analysed. This is much lower than expected and OPCS-4 codes are not being consistently used in a hospital setting to code rehabilitation encounters. While it is possible to link cancer patients known to the cancer registry to HES records, it is not possible to see if the hospital episode is due to the cancer or for another reason. It should be assumed that some of these already small numbers are due to comorbidities and are not cancer related. It appears that cancer registry-HES linked data is not a feasible data source for the needs of this project.

### 3.2 Planning session findings

The results of the planning session included a definition of the aims for the report, potential data sources, and a prioritisation of sources to follow up. Some ideas identified for further follow up included targeted interview or peer review with service providers who are known to have existing datasets, examining treatment summaries, READ codes, and patient reported outcome measures (PROMs). These results can be found in Appendix C.

### 3.3 Key themes and findings from interviews

The series of interviews undertaken from May to August 2017 revealed several overarching themes that frequently came up in more than one interview. An evaluation process was undertaken where Karen Robb and Molly Loughran met and reviewed field notes to identify key themes and collate supporting documentation into the those groupings. Five themes were identified during are described below.

#### *a. Challenges and complexities with current data collection*

The **recommendation** based on these findings states that any data collected needs to be clinically viable, pragmatic and low burden to those doing the work.

The first two interviews took place with two rehabilitation clinicians, Lindsay Farthing and Sam Tordesillas as a means of gaining insight into cancer rehabilitation in general, what data is currently collected in varied cancer rehabilitation settings and what challenges there are to data collection.

These interviews highlighted that collecting data which covers a complex range of tumour types, settings, and interventions will be challenging.

Rich, robust data exists in the individual provider centres, and may be filtered up to trusts or commissioners providing funding and oversight. However, there is no standardised collection of data. Most detailed data or outcomes data reporting is project or funding-specific and will only be collected on a cohort of patients for a limited duration of time. Any further requirements for data collection should take into account the impact of the clinician time required to collect and submit the data. Frequently, outcomes information is available in the patient's treatment notes but is not easily abstracted. Administrative statistics (e.g. referrals, appointment activity, and demographic details) are often regularly collected, but not collated at a pan-London level.

Tumour-specific measures will be difficult to collect as the rehabilitation needs for different tumour types vary and tumour-specific data collection would be burdensome, as is seen in the Cancer Outcomes and Services Dataset (COSD) which flows into the cancer registry. Keeping to a generalised set of data, without much tumour or intervention-specific data will be easier to achieve.

Rehabilitation providers are often multi-disciplinary and may not just see patients with cancer. When examining data using pathway or service line metrics, it can be challenging to identify and connect rehabilitation services to those who have a cancer diagnosis with current NHSE acute care data.

#### ***b. Demonstrating impact and value of cancer rehabilitation***

It is **recommended** that collected data should be used to demonstrate impact at the patient or societal level.

Any data collected should be able to be used to demonstrate impact or value of cancer rehabilitation services. These effects should be split into two categories:

- Showing impact at the patient level, e.g. improved access or outcomes
- Showing impact at the wider societal level, e.g. economic value of services

The theme of demonstrating value appeared in most of the interviews, recognising that the burden of collecting the data needs to be balanced by the benefits. In order to make recommendations, it needs to be determined what good looks like. This can be achieved using data, but it has to be appropriate data that show benefits. Hypotheses also need to be developed to determine what questions are being asked of the data before determining what data to collect.

Thoughts on how the data could be used to show the added value of AHPs included improving patient flow, providing alternate pathways, showing cost data, managing multi morbidities, e.g. frailty, and lessening the care burden. Learning from the project could also be used to demonstrate value in related areas such as psychological care for cancer patients.

#### ***c. Linking with strategic priorities and existing workstreams***

These findings lead to the **recommendation** that all data collected in the proposed dataset should be linked to strategic priorities and existing work where possible.

Any data collected should be tied to national strategic cancer priorities (e.g. Recovery Package and Stratified pathway) and existing national workstreams (e.g. Long term conditions agenda and Quality of Life metric) to receive greater buy-in and ease of collaboration. This will also allow

for longevity of data collection and increased utility of data collected. By tying the cancer rehabilitation dataset work to existing strategic priorities and commissioning guidance documents, the resulting dataset will be available to support the realisation of those priorities. Interviews from the clinical rehabilitation leads indicated that additional time requirements, like data submission, should be tied to strategic priorities to achieve buy in from clinicians.

Care should also be taken to align definitions within the dataset to these strategic requirements. Any data collected using a list of options (e.g. drop down list or tick box options) should use existing sources like national standards and guidance documents where appropriate, however clinical and service user review of a list options is critical. Any suggested changes from standard lists should be weighed against need for future list maintenance. Findings from meetings and interviews indicated that the current 'reason for rehab' list from the NHS England Commissioning Guidance for Rehabilitation<sup>12</sup> would need modifying for cancer clinicians and service users.

There are several national priorities set out to address various aspects of improving care, experience, and outcomes for cancer patients, and these priorities are not always synchronised. For example, implementing the Recovery Package, addressing consequences of treatment, and improving access to rehabilitation services are sometimes seen as separate priorities when they are inextricably linked. Focussing on patient centred care (e.g. faster response to patient needs and improving service design) is essential. This emphasises the need to link in with other strategic priorities that have similar remits to prevent gaps and competing methods.

The Quality of Life metric, when developed, will be an opportunity for alignment with the rehabilitation data project as it is related to national strategic priorities. The Independent Cancer Taskforce has set out recommendations to collect a Quality of Life (QOL) metric which can be linked to data held in the registry. This metric is currently being piloted by NHSE with an aim of a national roll out of the metric by February 2019. The metric will take an aggregated score to represent the overall health-related quality of life of people 12-24 months post cancer treatment. The aggregated score will be based on two validated patient reported outcome measures (PROMs). The two PROMs being piloted are the EQ5D (not cancer specific) and the EORTC QLQ-C30 (cancer specific). The data collected is also intended to be available back to treating clinicians in 'near real time'. Data will be able to be linked to other datasets using NHS number.

While the Quality of Life data isn't available currently, it has national strategic priority and will be important to consider going forward. This is because the 12-24 months post cancer treatment time frame is important in the rehabilitation pathway to show both effects of timely rehabilitation intervention and need for further rehabilitation. It was also noted that consequences of treatment are not intended to be captured by the Quality of Life metric. While the instruments used for the QOL metric do cover some consequences of treatment, the metric will not provide numbers of people with particular consequences. It will provide scores based on how certain issues impact on an individual's QOL (e.g. instead of showing how many people have mobility issues, it would show how many people report that mobility issues impact significantly on their QOL).

As the QOL metric is still being piloted, collecting additional PROMs in the cancer rehabilitation dataset was also considered. As shown in the *Cancer rehabilitation: a scoping report for*

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<sup>12</sup> Commissioning Guidance for Rehabilitation <https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf>



London<sup>13</sup>, patient reported outcomes are inconsistently collected. The options for the recommended dataset would either need to specify a PROM to collect (and when or how to collect it) or to ensure that data collected can be linked to the QOL metric to be collected consistently by 2019. This decision would need to balance benefits of consistent PROM collection with the potential burden on those collecting and submitting data. Connecting the cancer rehabilitation data project to a strategic cancer priority provides additional value to the QOL measure and allows potential for greater standing and recognition of the planned rehabilitation dataset. However, ensuring that the nationally collected QOL metric is associated to the time in which the service user is receiving rehabilitation services will be important. It would also require the NHS number to be collected for linking purposes.

An NHS Improvement tool currently in alpha (prototype development phase) is the Model Hospital. This provides a dashboard to NHS trusts to allow them to compare productivity, quality and responsiveness as well as to have a clearer view of improvement opportunities. It is organised around service lines, including cancer services as well as an allied health professional (AHP) compartment. However, data is limited currently to acute trusts and AHPs may work across service lines, not just in cancer so it is difficult to identify and extract data specific to cancer rehabilitation. Future integration with the Model Hospital would be valuable as there is a potential need for cancer rehabilitation data within the Model Hospital tool and it is set up to add data modules as they become available.

#### **d. Use a phased approach for piloting dataset**

It is **recommended** that the proposed dataset be implemented using a phased approach.

As robust data for cancer rehabilitation pan-London is not readily available, it is clear that a new dataset should be developed and collected. Jason Petit, senior cancer intelligence lead for TCST, advises that learnings can be taken from the development of other established cancer datasets: Any new dataset needs to be short, manageable, and easy to collect. Starting small with the potential to grow is recommended over trying to collect too much at the launch of a dataset. Audit-based collection is a good starting point, as barriers such as information governance considerations, and technical issues of where to hold the data would be lower.

Launching a new dataset is a significant undertaking and achieving buy in and success will be difficult if it is attempted in one step. A phased approach was suggested, as it allows for more difficult parts of the datasets to be addressed after initial success is achieved and learnings from prior phases applied. It is recommended that London adopts a three step approach:

**Phase 1:** Initial minimum dataset piloted, using an audit methodology

**Phase 2a:** Learnings from pilot applied and dataset rolled out

**Phase 2b:** Investigate whether pilot data is adequate for addressing unmet need

**Phase 3:** Apply learnings from phase 2 roll out and add in items that couldn't be included in phase 2. These items are detailed in Section 4.2.

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<sup>13</sup> Cancer rehabilitation: a scoping report for London  
<https://www.healthylondon.org/sites/default/files/Cancer%20rehabilitation%20-%20a%20scoping%20report%20for%20london.pdf>

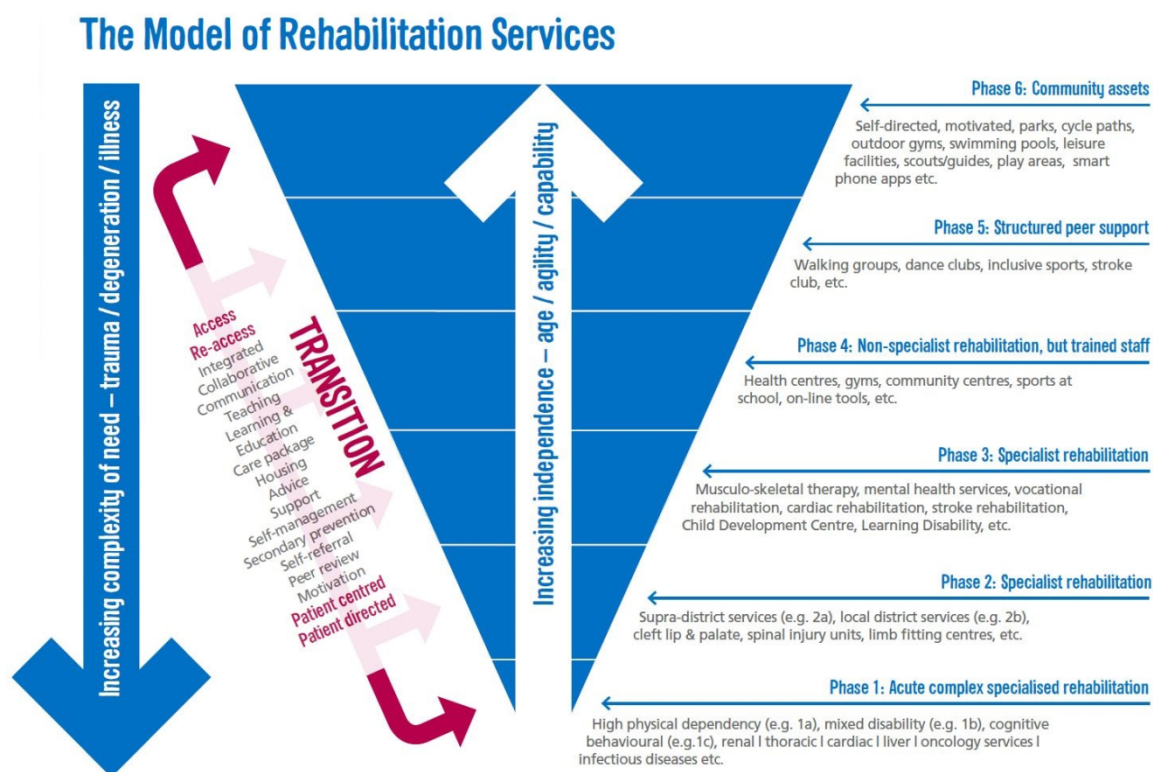


### e. Represent the full spectrum of rehab services

It is recommended that the proposed dataset be designed to incorporate the full spectrum of cancer rehabilitation services:

There is a spectrum of rehabilitation services and during a cancer patient's journey; they may require several services from varying levels of complexity at different times in the pathway. Many rehabilitation sites, especially those housed within trusts will have both acute and outpatient rehabilitation services. Care should be taken to ensure that data collected is easily collated for all types of services. As rehabilitation and allied health professional (AHP) services vary, care should also be taken to ensure that all types of rehabilitation are captured.

As confirmed by David Jillings, a service user interviewed, many services considered as rehabilitation don't fall into the traditional acute/specialist and non-specialist services, and include peer support and community assets. It is important to consider these types of services when designing an audit or pilot to get representation from all types of services. An example of the spectrum of services is shown in Figure 3.1



**Figure 3.1 Model of Rehabilitation Services reprinted from Commissioning Guidance for Rehabilitation<sup>14</sup>**

<sup>14</sup> Commissioning Guidance for Rehabilitation <https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf>

## 4 Recommendations and Next Steps

### 4.1 Proposed minimum dataset for cancer rehab

It is clear that there is no existing dataset that can support the aims of the TCST cancer rehabilitation workstream and the needs of commissioners in London.

The main recommendations of this report are that a dataset should be developed to address the lack of cancer rehabilitation data available and that the dataset should be implemented in a phased approach, as outlined in Section 3.3d.

This dataset should meet the following requirements:

- Be minimally burdensome to those contributing to it, while collecting clinically viable data.
- Be simple and realistic initially, developing as the work proceeds
- Measures collected should contribute to the stated objectives outlined in Section 1.3.
- Demonstrate impact at the patient or societal level.
- Data to be collected should be linked to strategic priorities and existing work.

To ensure the measures can be collected, and that they provide valuable information, the dataset should be agreed, piloted, and then collected in the form of a pan-London audit. This audit will align with additional TCST rehabilitation work where rehabilitation provider mapping is to take place. The task and finish group has developed and agreed the following recommended minimum dataset, found in Table 4.1. A more detailed description of the dataset, including definitions for options within each data point refer to Appendix E.

**Table 4.1 Proposed cancer rehab minimum dataset as agreed by task and finish group**

Question Group	Question
<b>Demographic</b>	<ul style="list-style-type: none"> <li>• Age</li> <li>• Sex</li> <li>• Ethnicity</li> </ul>
<b>Cancer History</b>	<ul style="list-style-type: none"> <li>• Cancer type</li> <li>• Date of diagnosis</li> <li>• Cancer treatment</li> <li>• Stage of treatment</li> </ul>
<b>Provider</b>	<ul style="list-style-type: none"> <li>• Date form completed</li> <li>• Name of provider</li> <li>• Provider type</li> <li>• Setting</li> <li>• Provider profession</li> </ul>

<b>Therapy</b>	<ul style="list-style-type: none"> <li>• Date of referral and referrer</li> <li>• Reason for rehabilitation</li> <li>• Treatment received</li> <li>• Details of any other non-cancer related rehab for another issue?</li> <li>• Number of visits - one to one and group</li> <li>• Discharge Status</li> </ul>
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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 4.2 Items not recommended for collection in phase 1 but identified as items valuable to collect**

<b>Item</b>	<b>Reason for not collecting</b>
<b>NHS Number</b>	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.
<b>Patient Reported Outcome Measure</b>	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.
<b>SNOMED codes for reported symptoms and treatments given</b>	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.
<b>Comorbidity</b>	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.

## 4.2 Next Steps

The proposed minimum dataset has been presented to the London LWBC Partnership board and pan London Intelligence Group for discussion and endorsement prior to piloting. Following piloting, the dataset will be presented to the Cancer Commissioning Board (CCB) for discussion and ratification prior to publication. Future work will take a phased approach as follows:

**Phase 1** Initial minimum dataset piloted pan London, using an audit methodology.

This should run alongside the future mapping of cancer rehabilitation services and compiling workforce data, as described in the work plan of the *Cancer rehabilitation: a scoping report for London*<sup>3</sup>. This process will require support from key stakeholders across London, namely the strategic leads for cancer rehabilitation (or equivalent) in the Cancer Alliances, STP geographies and CCGs.

**Phase 2a** Learnings from pilot and audit applied and dataset rolled out with any necessary changes based on results from pilot.

As phase 1 data would be collected through audit processes, processes for systematic collection of data and compliant storage of the data would need to be developed.

**Phase 2b** Addressing unmet need.

At a service provider type level, numbers of patients receiving interventions could be compared to other datasets with information on cancer patients to get an estimation of those who are not receiving that specific rehabilitation service type. However, other ways to investigate unmet need may be revealed in phases 1 and 2 which may lead to separate projects.

**Phase 3** Apply learnings from phase 2 roll out and add in items that couldn't be included in phase 2.

These are listed in Table 4.2.

As the development of a cancer rehabilitation dataset is an iterative process, TCST will continue to engage with major stakeholders to refine the tool and develop methodology as we proceed with this work.

## 5 Appendices

### Appendix A – Membership and roles of Cancer Rehabilitation Data task & finish group

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

## Appendix B – Data scoping results

Code	Group description	Detail description	Count
U542	Rehabilitation for other disorders	Delivery of rehabilitation for respiratory disorders	91
U548	Rehabilitation for other disorders	Other specified rehabilitation for other disorders	79
U543	Rehabilitation for other disorders	Delivery of rehabilitation for stroke	36
X602	Rehabilitation assessment	Rehabilitation assessment by multidisciplinary specialised team	35
U508	Rehabilitation for musculoskeletal disorders	Other specified rehabilitation for musculoskeletal disorders	29
U549	Rehabilitation for other disorders	Unspecified rehabilitation for other disorders	24
U502	Rehabilitation for musculoskeletal disorders	Delivery of rehabilitation for hip fracture	16
U541	Rehabilitation for other disorders	Delivery of rehabilitation for acute cardiac disorders	15
U518	Rehabilitation for neurological disorders	Other specified rehabilitation for neurological disorders	13
U503	Rehabilitation for musculoskeletal disorders	Delivery of rehabilitation for joint replacement	11
U512	Rehabilitation for neurological disorders	Delivery of rehabilitation for spinal cord injury	10
U501	Rehabilitation for musculoskeletal disorders	Delivery of rehabilitation for amputation of limb	<6
U505	Rehabilitation for musculoskeletal disorders	Delivery of rehabilitation for osteoarthritis	<6
U519	Rehabilitation for neurological disorders	Unspecified rehabilitation for neurological disorders	<6
U522	Rehabilitation for psychiatric disorders	Delivery of rehabilitation for alcohol addiction	<6
U511	Rehabilitation for neurological disorders	Delivery of rehabilitation for brain injuries	<6
X603	Rehabilitation assessment	Rehabilitation assessment by unidisciplinary non-specialised team	<6
X601	Rehabilitation assessment	Rehabilitation assessment by multidisciplinary non-specialised team	<6
U531	Rehabilitation for trauma and reconstructive surgery	Delivery of rehabilitation following plastic maxillofacial reconstructive surgery	<6
U534	Rehabilitation for trauma and reconstructive surgery	Delivery of rehabilitation for trauma nec	<6

## Appendix C – Planning session notes

Priority	Source	Notes
✓	<b>Learnings from other types of rehab</b>	<ul style="list-style-type: none"> <li>• Orthopaedics, stroke, neuro were suggested. Karen Robb highlighted neuro as a good place to start</li> </ul>
	<b>Treatment summary info</b>	<ul style="list-style-type: none"> <li>• Pawan Randev suggested that the treatment summaries coming back from rehabilitation providers to GP practices are structured so data is being captured</li> </ul>
✓	<b>READ codes + CCR</b>	<ul style="list-style-type: none"> <li>• WHO Classifications?</li> <li>• Research Ready Federations</li> <li>• Sarita Yaganti agreed to help take forward through LTC working group.</li> </ul>
	<b>Service Providers</b>	<ul style="list-style-type: none"> <li>• Peer review audits</li> <li>• Existing data</li> <li>• Over and above datasets (Lindsay Farthing (Barts Health), Sam Tordesillas (CHANT))</li> </ul>
	<b>PROMs/Pt. Experience</b>	<ul style="list-style-type: none"> <li>• Qualitative</li> </ul>
✓	<b>HWB event data?</b>	<ul style="list-style-type: none"> <li>• What do HWB events offer</li> <li>• HNAs along pathway</li> <li>• Macmillan</li> </ul>
	<b>HNA &amp; care planning data</b>	<ul style="list-style-type: none"> <li>• Third sector?</li> <li>• Sample data</li> <li>• Social prescribing service</li> </ul>
	<b>PHE/Macmillan data?</b>	
	<b>Treatment data in services?</b>	<ul style="list-style-type: none"> <li>• Surgery</li> <li>• Radiology</li> <li>• Chemotherapy</li> <li>• Stratified follow up</li> <li>• MDT</li> </ul>
✓	<b>Focus area: common cancers</b>	<ul style="list-style-type: none"> <li>• Look at more well established vs. less well established</li> </ul>
	<b>Lymphoedema</b>	<ul style="list-style-type: none"> <li>• Look at those with lymphoedema and track back</li> </ul>
	<b>Education to patients</b>	

## Appendix D – List of stakeholders interviewed

<b>Sam Tordesillas</b>	Outpatient Rehabilitation Clinical Team Lead Guy's and St. Thomas' Community Head and Neck Cancer Team
<b>Lindsay Farthing</b>	Clinical Lead for Oncology Therapies, St. Bartholomew's Hospital
<b>Sarah Benger</b>	Senior Programme Manager, LWBC, NHS England
<b>David Jillings</b>	Service User and Trustee, the Pelvic Radiation Disease Association
<b>Jason Petit</b>	Senior Cancer Intelligence Lead, TCST
<b>Andrew Nwosu</b>	Allied Health Professionals Lead for London, NHS England
<b>Joanne Fillingham</b>	Clinical Director Allied Health Professions (AHPs) & Deputy Chief Allied Health Professions Officer, NHS Improvement



**Appendix E – Proposed cancer rehabilitation dataset with definitions**

<b>Question group</b>	<b>Question no.</b>	<b>Question</b>	<b>Response options</b>
<b>Demographic</b>	1	Age	(free text)
	2	Sex <sup>15</sup>	male female unspecified or other
	3	Ethnicity <sup>16</sup>	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

<sup>15</sup> 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>

<sup>16</sup> Categories derived from NHS data dictionary [http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/e/end/ethnic\\_category\\_code\\_de.asp](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 <sup>17</sup>	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 <sup>17,18</sup>	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

<sup>17</sup> 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](https://digital.nhs.uk/media/896/National-Cancer-Waiting-Times-Monitoring-Dataset-Guidance/pdf/National_Cancer_Waiting_Times_Monitoring_Dataset_Guidance)

<sup>18</sup> 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 <sup>19</sup>	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)

<sup>19</sup> 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 <sup>20,21,22</sup>	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)

<sup>20</sup> 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.

<sup>21</sup> Multiple selections will be allowed i.e. participants can select as many options as needed.

<sup>22</sup> 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 <sup>23</sup>	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? <sup>24</sup>	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? <sup>24</sup>	Yes (add detail as free text) No

<sup>23</sup> 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

<sup>24</sup> 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.

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