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# **Cancer rehabilitation: a scoping report for London**

Transforming cancer services team, February 2017

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## Executive summary

This report is the result of a project undertaken by the Transforming Cancer Services Team (TCST) for London to better understand the scope of cancer rehabilitation services in London and to inform the development of future commissioning guidance for cancer rehabilitation. TCST engaged with multiple stakeholders between April and December 2016, and the work was fully funded by Macmillan Cancer Support.

This report is targeted primarily at commissioners but will also be helpful for providers, service users, the third sector and others. Although the focus of this work is on cancer rehabilitation, the findings have relevance beyond cancer.

The report contains five main sections:

1. Strategic context and relevant background
2. A summary of the 'Cancer Rehabilitation Task and Finish Group' activities
3. Analysis of a stakeholder engagement event
4. Analysis of focus groups with commissioners
5. Conclusions, next steps and work plan for 2017/18.

Triangulating data from the cancer rehabilitation task and finish group, the stakeholder engagement event and the focus groups with commissioners has provided clear and consistent messages around the issues and challenges with cancer rehabilitation, and how these can be tackled with future commissioning guidance. There are significant gaps in cancer rehabilitation services and the rehabilitation workforce across London, and there is evidence that this impacts on patient care. The key challenges for improving the commissioning of cancer rehabilitation services include:

- Poor understanding of the economic benefits of good rehabilitation.
- The lack of good data on cancer rehabilitation services.
- Poor awareness and understanding of the breadth and scope of cancer rehabilitation.
- The complexity of commissioning processes.
- Increasing needs and complexity of service users.
- Education and training needs of the wider workforce.
- System leadership.

In summary:

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

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. The three cancer alliances in London and local champions will play a key role in helping drive this agenda forward.
- Implementation of the guidance will be complex and challenging but can be supported by linking cancer rehabilitation to national and regional directives (e.g. The Recovery Package, stratified follow-up and the integrated care agenda) and local priorities, particularly those identified in sustainability and transformation plans (STPs).

Moving forward, TCST will convene a multidisciplinary Cancer Rehabilitation Steering Committee to oversee a workplan for 2017/18 that includes:

1. Producing commissioning guidance that builds on findings from this scoping report
2. Developing a suite of tools that support the commissioning of rehabilitation services
3. Providing system leadership on cancer rehabilitation.

The priority for the steering committee is to finalise the scope of future commissioning guidance and timelines for deliverables. Decisions will be ratified by the TCST Living With And Beyond Cancer Board.

## Acknowledgments

The Transforming Cancer Services team (TCST) acknowledge the support we received from a wide range of stakeholders in preparing this report. Our thanks go to the Cancer Rehabilitation Task and Finish Group (see Appendix 1), everyone who attended and contributed to our stakeholder engagement event and all the participants in our focus groups. A special thank you to Macmillan Cancer Support for funding this work, and especially to June Davis for her expert guidance.

## Introduction

*“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 the 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

The purpose of this scoping report is to present the findings from extensive stakeholder engagement designed to shape commissioning guidance for cancer rehabilitation. It is specifically targeted at commissioners, but also to all stakeholders with an interest in cancer rehabilitation, including providers, service users, the voluntary sector and others across the spectrum of health and social care. Although the focus of this work is on cancer rehabilitation, we believe the findings are also relevant for other rehabilitation services.

Dr Karen Robb (KR), Macmillan Rehabilitation Clinical Lead for TCST, led this work and authored this report and her post was fully funded by Macmillan Cancer Support from April 2016 to December 2016. Liz Price, Senior Strategy Lead for Living With and Beyond Cancer (LWBC) supervised the project. Project support came from the LWBC team, and June Davis, National Cancer Rehabilitation Lead, Macmillan Cancer Support provided additional advisory support.

This report contains five sections:

1. Background and strategic context
2. A summary of the ‘Cancer Rehabilitation Task and Finish Group’ activities
3. A write up of the stakeholder engagement event
4. Analysis of focus groups with commissioners
5. Conclusions and next steps

## 1. Background and strategic context

### 1.1 An overview of rehabilitation and cancer rehabilitation

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'<sup>1</sup>.*

NHS England considers rehabilitation as being, 'everyone's business' and the Medical Director, Sir Bruce Keogh, has stated that, 'rehabilitation is now central to the way we deliver our health services'<sup>1</sup>.

Cancer rehabilitation plays an important role in the care of people living with and beyond cancer<sup>2</sup>, 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. 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:

- Preventative: reducing impact of expected disabilities and improving coping strategies
- Restorative: returning an individual to pre-morbid 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 management<sup>3</sup>.

### 1.2 National context

Cancer is a strategic priority for NHS England. There is growing recognition of the need to improve care for people living with and beyond cancer<sup>4</sup> and the lack of attention given to managing the consequences of cancer treatment in the NHS has been highlighted by Macmillan Cancer Support<sup>5</sup>. A national strategy for England was published in July 2015 with 96 recommendations for improving care<sup>6</sup>. This was followed by an implementation plan in May 2016<sup>7</sup> which highlighted how the recommendations would be rolled out nationwide. Recent commissioning guidance from NHS England<sup>8</sup> supports access to the Recovery Package and stratified follow up pathways (both highlighted in the Cancer Taskforce recommendations<sup>6</sup>) and the new NHS operational planning and contracting guidance has mandated local implementation of these initiatives<sup>9</sup>.

Cancer rehabilitation is a vital ingredient in managing the consequences of cancer treatment and must be considered alongside, and fully integrated with, initiatives such as the Recovery Package, to optimise quality of life and functioning for patients.

Rehabilitation in cancer care is gaining increasing recognition through a dedicated national work programme led by Macmillan Cancer Support. The Macmillan work programme has six main strands:

1. Understanding cancer rehabilitation
2. Raising the profile of cancer rehabilitation
3. Developing leadership in the rehabilitation workforce
4. Education, training and support to provide cancer rehabilitation
5. Building the evidence base for cancer rehabilitation
6. Developing rehabilitation teams fit for the future.

An important product of the work so far is the development of an allied health profession (AHP) competency framework, which is now being piloted across the UK. Work is also underway to update, and bring online, evidence-based rehabilitation pathways produced by the National Cancer Action Team (NCAT) (N.B. this work lost momentum when NCAT was disbanded in 2013).

### 1.3 Local context

The commissioning landscape within London is complex and challenging with 32 CCGs, five sustainability and transformation planning (STP) footprints and three cancer delivery systems, two of which are national cancer vanguard sites.

Mapping of the specialist cancer AHP workforce in London by both London Cancer\* and London Cancer Alliance\*\* (LCA) has shown a significant shortfall in specialist posts. LCA published their findings in 2014<sup>10</sup> 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<sup>10</sup>. There is a significant opportunity for transformational change in cancer rehabilitation services through the sustainability and transformation plans (STPs) and the three cancer delivery systems (Royal Marsden Partners Vanguard, UCLH/London Cancer Vanguard and South East London Accountable Care Network).

\* London Cancer: This was part of UCL Partners and was the integrated cancer system serving North East and Central London and West Essex. It transitioned to become part of the national cancer vanguard (now known as the UCLH Cancer Collaborative) in Sept 2016.

\*\* 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 the Royal Marsden Partners Vanguard (covering North West and South West London) and the South East London Accountable Care Network.



## 2. Cancer Rehabilitation Task and Finish Group

A task and finish group was established to oversee the TCST work on cancer rehabilitation. The group was chaired by KR and included representation from the TCST, service users, provider organisations, commissioning, the cancer delivery systems and the third sector. Members met four times over the course of the project (in May, June, October and December 2016) with some of the work done virtually. See Appendix 1 for the membership of the group.

The group was pivotal in providing subject knowledge and ‘on the ground’ experience and ensured the project had relevance and appropriate direction. Some key contributions are outlined below.

- The group provided significant detail on the top three issues/challenges in cancer rehabilitation. A wide range of issues were discussed, all of which are relevant to the production of commissioning guidance. Issues included:
  - funding challenges
  - gaps in services and multiple unmet needs across many tumour groups
  - lack of knowledge and awareness of cancer rehabilitation in the wider system
  - lack of sufficient care throughout the entire pathway
  - workforce training needs
  - lack of sharing/dissemination of good practice and good practice models
  - insufficient data on rehabilitation services
  - the need to link cancer rehabilitation with work on the Recovery Package and stratified follow-up.
- The group contributed to and helped shape the stakeholder engagement event (see Section 3) and gave feedback on the format of the focus groups with commissioners (see Section 4).
- The group helped shape the scoping report on cancer rehabilitation.
- The group helped shape the TCST cancer rehabilitation work plan for 2017/18 and the proposed content for future commissioning guidance (see Section 5.2).

Some questions remain outstanding around the scope of future commissioning guidance, and these relate particularly to the overlap with mental health services.

## 3. Cancer rehabilitation stakeholder engagement event

### 3.1 Aims and objectives

The main aim of the cancer rehabilitation stakeholder engagement event was to bring together stakeholders from across London to help shape future commissioning guidance for cancer rehabilitation. Key objectives of the event were to:

- Engage with delegates from all five STP footprints in London.
- Discuss key issues from a service user, provider and commissioner perspective.

- Update delegates on national and regional work programmes.
- Facilitate networking and small group discussions.
- Encourage feedback to TCST on issues related to cancer rehabilitation.

### 3.2 Attendance

A total of 53 delegates attended the event at Southwark Cathedral in London on 15 June 2016, and this was inclusive of 8 TCST staff and the facilitators and speakers. The breakdown of attendees per geographical area and stakeholder category is shown in Appendix 2. There was good representation from most areas in London, with the exception of North Central London, which was underrepresented. There was excellent representation from providers and a reasonable number of service users and delegates from the charitable sector. Only two commissioners attended the event.

### 3.3 An overview of the event programme

A copy of the programme is shown in Appendix 3. The event included:

- A presentation by a service user outlining the physical and emotional consequences of his treatment for pelvic cancer. This talk generated much discussion around the importance of preparing patients well for the consequences of treatment.
- An 'icebreaker' where each table discussed examples of best practice in cancer rehabilitation. Table discussions were followed by a 'fast feedback' session to the main group. Further details on the findings of this session are discussed in Section 3.4.1.
- Presentations and a panel discussion to update the delegates on key strategic issues in rehabilitation. Presentations were delivered by representatives from NHS England, Macmillan Cancer Support, TCST, London Cancer and South East London Accountable Care Network.
- Table discussions using clinical case studies to highlight gaps in services and principles that should be considered in future TCST commissioning guidance. Further details on this session are discussed in Section 3.4.2.

Networking and discussions were encouraged throughout the day and delegates were invited to add additional comments on 'post-it' notes.

## 3.4 Findings from table conversations

### 3.4.1 'Ice-breaker' session: discussing good practice in cancer rehabilitation

This was a facilitated session and notes of the discussions are presented in Appendix 4. Delegates had detailed discussions and some clear themes emerged as being important for good cancer rehabilitation including:

- A multidisciplinary/multi professional team approach.
- Seamless, co-ordinated care, managing transition points and linking well with other services.
- Person-centred, holistic care.
- A focus on quality of life and wellbeing.
- A focus on managing consequences of treatment.
- Improving ability to self-manage and take control.
- Early intervention and care throughout the pathway.
- Well-evaluated services able to demonstrate impact and outcomes, including economic impact.

### 3.4.2 Discussion of clinical case studies

This was also a facilitated session with delegates divided into their geographical areas. A summary of the discussions is presented in Appendix 5. The summary points for each case study, which are relevant for commissioning guidance, are as follows:

#### 1) B cell lymphoma with spinal cord compression: complex neurological rehabilitation.

- Lack of rehabilitation beds is causing long in-patient stays in London.
- Education of the workforce is needed to change attitudes towards rehabilitation and improve patient experience.
- Virtual wards are an option for care.
- Supporting palliative patients within rehabilitation settings is important.

#### 2) Rectal cancer: post-operative rehabilitation:

- Learning from other referral pathways e.g. stroke is important.
- Consider care navigator roles.
- Improve the awareness of rehabilitation within senior management teams.
- Better integration is needed between health and social care.

#### 3) Low grade brain tumour: therapy team and psychology interventions:

- Medical needs can be specialist but rehabilitation needs may be generic.
- Empowering carers is key.
- Keyworker roles in primary care are important.
- Shared access to records is important.
- Better data is needed e.g. waiting times for rehabilitation.

#### **4) Breast cancer: physical activity scheme**

- Prehabilitation is important.
- A clear, concise exercise plan for patients is needed.
- Mental health issues are as important as physical health.
- Compassion fatigue exists in healthcare professionals and needs to be addressed.
- Move rehabilitation into the community more and join up rehabilitation services where possible.

#### **5) Lung cancer: in-patient rehabilitation**

- Embed rehabilitation throughout the pathway.
- A generic cancer pathway may be better than tumour specific.
- Holistic needs assessments are crucial: address mind and body.
- A designated point of contact is needed.
- Upskilling the generic workforce is vital.
- IT challenges exist.

#### **6) Breast cancer: post-operative rehabilitation**

- Prehabilitation is very important.
- Treatment should be based on patient need and not finances.
- AHPs need to be better integrated into multi-disciplinary teams.
- Patients need better access to services and better co-ordination of care to prevent feeling abandoned.

#### **7) Laryngectomy: post treatment**

- Community rehabilitation is needed at key parts of the pathway.
- Increased awareness is needed of the role of AHPs.
- Better data is needed on the cost savings associated with rehabilitation services.
- Education of the workforce is needed and specialists have a role in educating non-specialists.
- We need to improve relationships between patients and GPs re: rehabilitation.

### **3.5 Actions and challenges for cancer rehabilitation: a summary of delegates' comments**

Delegates provided information on the key challenges facing cancer rehabilitation services and the actions needed via 'post-its' on a comments board. The data is shown in Appendix 6.

### 3.5.1 Challenges

A wide range of challenges were discussed, many of which are complex and multifactorial. It is clear that cancer rehabilitation services are not being optimally commissioned and there is a lack of data demonstrating the economic impact of good rehabilitation. Delegates discussed the pressures on services due to compassion fatigue, recruitment and workforce challenges and low staff morale. They expressed concerns with the increasing demand on services meaning clinicians struggle to provide good clinical leadership alongside providing care for patients. Evaluating services well and learning from other conditions management, such as palliative care and long-term conditions, were also discussed.

Delegates discussed the challenge of culture change and improving the profile of rehabilitation with Trust boards and awareness of rehabilitation with GPs. They found linking services together and knowing what other services are available for patients were both challenges for many.

### 3.5.2 Actions

A wide range of actions was recommended to improve cancer rehabilitation services and these spanned the entire pathway. The actions have been listed below under three key themes, which are relevant to the development of commissioning guidance.

#### **Improving quality of services:**

- Routine access to rehabilitation.
- Early intervention.
- Improve evaluation.
- Patient engagement in developing strategies.
- Psychological care is fully embedded.
- Better co-ordination of care.
- Better workforce education and training.
- Rehabilitation integrated within long term conditions management.

#### **Improving profile and awareness of rehabilitation:**

- Raise awareness of the lack of services.
- Strategic level engagement of AHPs.
- Increased exposure to oncology for students and newly qualified staff.
- Networking and sharing information and resources.

#### **Improving funding of services:**

- Improve funding mechanisms.
- Succession planning.
- Training for staff in business case development.

### 3.6 Evaluation of the event

Thirty-four evaluation forms were analysed and the vast majority of delegates rated the venue and speakers as excellent or good. The most useful aspects of the event were an opportunity to network, the table discussions, an opportunity to get updated on regional and national work, and the opportunity to hear from service users. Delegates expressed an interest in learn more about the financial challenges and to have better engagement with commissioners. Many delegates were keen to stay involved with this work. Moving forward, the TCST needs to broaden engagement to include those working in other speciality areas.

Examples of some of the comments received are shown below:

- 'Very beneficial. Great to be a part of driving services forward'.
- 'Good networking opportunity and interactive group sessions to discuss on the ground issues'.
- 'A more candid discussion (needed) about how we tackle the fact that there is no money in the system'.
- 'Good event, shame there were not more commissioners, consultants, GPs'.

### 3.7 Summary

The cancer rehabilitation stakeholder engagement event was well evaluated and attracted a broad range of stakeholders from across London. There was poor attendance by commissioners and this required further attention. The event generated useful data to aid the development of commissioning guidance for cancer rehabilitation. Key findings from the day were:

- Demonstrating the economic impact of good cancer rehabilitation and commissioning for best value will be central to improving care across the system.
- The timing, quality and quantity of information are important when preparing patients for the consequences of treatment.
- Participants' descriptions of good rehabilitation services during the icebreaker session are consistent with those described in previous work by NCAT<sup>2</sup> and NHS England<sup>1</sup> and reflects aspects such as holistic, personalised care; seamless pathways of care; early intervention and care throughout the pathway, a focus on empowerment, quality of life and wellbeing and a focus on evaluation of impact and outcomes.
- There are significant gaps in cancer rehabilitation services across London spanning multiple pathways, acute and community care and health and social care settings.
- A wide range of challenges exists for cancer rehabilitation services, many of which are complex and multifactorial.
- Improving cancer rehabilitation needs to consider the profile and understanding of cancer rehabilitation, the funding of services, the quality and timing of care,

workforce issues, alignment with other services, data and metrics and service user engagement.

- A myriad of opportunities exist for improving cancer rehabilitation services.
- Stakeholders warmly welcome commissioning guidance.

### 3.8 Next steps

Outcomes from the engagement event were discussed with the Cancer Rehabilitation Task and Finish Group and it was agreed that further engagement with commissioners could be achieved through targeted focus groups. This work is discussed in Section 4.

## 4. Focus groups with commissioners

### 4.1 Aims and objectives

The main aim of the focus groups was to get detailed information from commissioners to help shape the content of future commissioning guidance for cancer rehabilitation. Key objectives were to:

- Engage with CCG commissioners from every STP area in London, and NHS England.
- Strengthen relationships between TCST LWBC team and commissioning colleagues.

### 4.2 Methods

#### 4.2.1 An overview of the planning

The format of the focus groups was adapted from previous work by TCST<sup>11</sup>, with the support of June Davis, the National Cancer Rehabilitation Lead for Macmillan Cancer Support. Each focus group was audio recorded (with the full written consent of participants) and lasted between 60 and 90 minutes. The format of the focus groups is shown in Appendix 7.

The themes explored within the groups were:

- Understanding of the scope and breadth of cancer rehabilitation.
- How rehabilitation services for people LWBC are currently commissioned.
- Improving the commissioning of these services.
- Implementation of the guidance and influencing change in the health and social care system.

## 4.2.2 Recruitment

Emails were sent to all cancer commissioning managers, contract managers and GP cancer leads in all 32 CCGs in London, plus West Essex CCG. Also, STP Leads and other key strategic roles were targeted. Attendees were sent preparatory reading before the event.

## 4.2.3 Data analysis

The audio recordings were fully transcribed by an external transcribing service, with only the chair of the focus group identifiable. Field notes were also used in the analysis. KR completed data analysis, with the support of June Davis.

Transcripts were shared with participants to establish the trustworthiness of data. Data for each of the three focus groups was tabulated under the following ten categories, which reflect the questions asked to participants:

1. Understanding rehabilitation/cancer rehabilitation.
2. Examples of good rehabilitation services.
3. How services are commissioned.
4. How decisions are made about commissioning.
5. Gaps in rehabilitation services.
6. Data collection.
7. Views on TCST commissioning guidance for lymphoedema services.
8. What to include in commissioning guidance for cancer rehabilitation.
9. What not to include in commissioning guidance for cancer rehabilitation.
10. Supporting implementation of guidance.

## 4.3 Results

### 4.3.1 Participants and representation

Three focus groups were run over a two-week period in September 2016. The first group was used as a pilot to refine questions and test the format. It involved clinical commissioning colleagues with a TCST role. A total of 11 commissioners participated in the focus groups with three attendees at group 1, five attendees at group 2 and three attendees at group 3. There was representation from six CCGs and NHS England. In total, four STP areas were represented, with no representation from SEL. The CCGs and corresponding STP areas represented were:

- Barnet CCG (NCL STP).
- Brent CCG (NWL STP).
- Hillingdon CCG (NWL STP).
- Merton CCG (SWL STP).
- Redbridge CCG (NEL STP).
- Waltham Forest CCG (NEL STP).



### 4.3.2 Analysis of transcripts

The main findings relevant to the development of commissioning guidance are discussed under the ten categories explored in the focus groups.

#### 1. Understanding rehabilitation/cancer rehabilitation

There was good agreement that the terms 'rehabilitation' and 'cancer rehabilitation' are not well understood in the wider system. There was good agreement that stakeholders, including participants themselves, don't fully understand the scope and breadth of rehabilitation, with many associating it with a particular part of the pathway.

*'It inhabits a certain place in my mind certainly which is post treatment as part of a package that would be ideal to develop' (FG 1).*

*'People tend to see rehab as that first bit after cancer treatment and then the end of life. And there's that gap in the middle. I don't think that is well recognised' (FG 3).*

It was recognised that the views of patients and clinicians may differ with potential for different answers to questions about rehabilitation. Participants in FG 3 disliked the term 'rehabilitation' with some advocating for use of the term 'survivorship'

instead.

*'The word survivorship is much more positive than I'm post cancer but under rehab' (FG 3).*

*'Rehab implies that the patient may have had treatment but you haven't quite finished the job' (FG 3).*

There was good agreement on the holistic nature of rehabilitation and the fact it encompasses physical, psychological, spiritual and social factors. Participants understood the need for a patient-centred approach and the links with improving quality of life. Some participants understood that rehabilitation spans the entire pathway and the value of early intervention, although few discussed prehabilitation.

*'In palliative care, huge potential to live well and improve quality of life' (FG 2).*

*'Cancer rehabilitation should start as soon as you start your treatment' (FG 2).*

Participants identified key features such as managing the consequences of treatment and a focus on function and goals setting. They also stressed the importance of educating and empowering patients.

*'..give them the tools to manage their health, so they're not coming back to make a repeat appointment with their GP because they're not coping or they don't know' (FG 2).*

Many participants raised the issue of determining what (if anything) distinguishes cancer rehabilitation as different from other types of rehabilitation. The overlap with other non-cancer specific services was identified and cited as important to acknowledge and understand.

*'I think one of the biggest challenges is working out or agreeing on what is specific to cancer, and what's not' (FG 2).*

*'Rehab for cancer is no different than rehab for non-cancer' (FG 3).*

## **2. Examples of good rehabilitation services**

Participants discussed a range of examples and why they were chosen. Examples included NHS services, and those provided by the charitable sector. Services not traditionally associated with cancer care were cited, including pulmonary rehabilitation and cardiac rehabilitation services. Participants repeated some of the important features of rehabilitation when justifying their choices i.e. holistic services, patient centred etc.

Participants also raised the importance of the economic benefits of services in keeping patients out of hospital, supporting patients in the community and supporting early discharge. The benefits of integrated teams, a single point of access and a single care plan were discussed. A particular reference to Improving Access to Psychological Therapy (IAPT) services was given in FG 3,

*'They have more than any other area I can think of, got their act together and they can measure outcomes. And they do Friends and Family Test with virtually every patient...they produce huge audits virtually overnight of three or four hundred patient. But that is not mirrored in other services' (FG 3).*

One participant suggested that good services are not always commissioned well (discussed further below).

*'...if this was a different question, if this was, can you give some examples of good, commissioned services, I would probably say none...but I can think of good services or good individuals who are good at providing rehab' (FG 1).*

## **3. How services are commissioned**

There is variation in commissioning processes and a lack of transparency in how services are commissioned. Services are currently fragmented, disjointed and poorly coordinated, and this impacts on patient care.

*'Certainly at the moment, it doesn't really feel like everyone necessarily knows what everybody else is commissioning' (FG 2).*

*'I think that there are areas that are well served. But they are very siloed at the moment and they're not joined up (FG 3).*

*'Commissioning processes make it difficult for people to access care' (FG 1).*

Rehabilitation is often commissioned through block contracts with service specifications quite broad. Measuring outcomes is difficult as unpicking the data can be challenging and there are often no metrics monitored beyond productivity.

*'It may be KPI'd but depends on whether there's a metric for it' (FG 1).*

*'They get a big pot of money to deliver a huge range of services and then it's really hard to get data out of them to know what's going on' (FG 1).*

The current shortfalls in commissioning appear to affect the sustainability of services and can leave services vulnerable.

*'And so when you lose that lead clinician, it's surprising how frequently the service disappears and I've seen excellent services, really excellent services that won national awards and all the rest of it, just disappear when the lead clinician goes' (FG 1).*

Rehabilitation does not appear to be a priority within STPs but some participants were optimistic that things would improve in the future with the focus on improving survival and managing recurrence. Some areas appear to be taking a more holistic view to cancer care with some CCGs starting to think about cancer as a long-term condition.

*'I think they're getting better at putting long term conditions management and self-management into a contract' (FG 1).*

#### **4. How decisions are made about commissioning**

The financial aspects are driving commissioning decisions and the economic benefits of services are central to decisions. One participant discussed a matrix system used in their CCG, which includes clinical efficiency, quality and the impact of not commissioning.

*'I think the current economic climate is really hard. It has to be definite savings, and in quite a short time' (FG 2).*

*'It's really hard to sell something that's going to develop a benefit in a longer time, because we want the savings now, and we are being monitored on how we are progressing with these things' (FG 2).*

Decision makers may not always have sufficient knowledge of rehabilitation and it feels important to understand the reasoning behind decisions made.

*'People making decisions may have no experience of the area' (FG 1).*

Participants discussed the importance of listening to the patient voice and ensuring that all groups of patients are adequately represented.

## 5. Gaps in cancer rehabilitation services

There are gaps in the provision of both NHS and social care outwith the recovery package provision. Particular reference was given to the lack of lymphoedema services.

*'But in terms of people once they've had their health and wellbeing event, what happens if something happens 2 weeks later? It's back to your point of where do they go to? They need to know there is support out there' (FG 3).*

*'I think there's a great big hole in the middle between end-of-life and just post treatment. A huge gap which needs to be filled. Which is partly filled by 3rd sector organisations. But there's nothing within the NHS and the local authority services which can easily be identified as supporting people in need' (FG 3).*

There are also gaps in knowledge of where services are and how to access them.

*'Does the GP know what that patient might need and how to access those different services?' (FG 2).*

The lack of services for younger adults, middle aged, the elderly, the dependants of people with cancer and bereaved children were all identified.

## 6. Data collection

It is recognised nationally and regionally that there is a lack of good qualitative and quantitative data on rehabilitation services. It is also recognised that more consistent and comparable data is needed.

*'The data is not really there' (FG 1).*

*'Often don't have KPIs or numbers' (FG 2).*

Participants cited many challenges including making data relevant, block contracts and separating out cancer from non-cancer data. Looking at 'Right Care' and linking data sets were suggested.

*'Have a look at this (Right Care). I know Right Care's not popular, but it's a benchmark. I think it's indicative to be honest' (FG 3).*

*'Linking, say, data on exercise and mobility. So if ... the more mobile you are, you know, the longer it is before you need care' (FG 1).*

## 7. Views on TCST commissioning guidance for lymphoedema services

Few participants were able to provide comment here. The document appeared to be valued, particularly the scene setting, the mapping of services and the service specification.

*'..really helpful to ensure everyone is on the same understanding at the start' (FG 3).*

*'..very helpful to get comparative data on CCGs' (FG 3)*

*'The time that's taken around debating what does good look like. It's in here. It's done. Actually, this is the model' (FG 3).*

It was acknowledged that although the Cancer Commissioning Board (CCB) had ratified the document, implementation is still challenging.

*'People understand why endorsed by CCB but the job is harder than that' (FG 1).*

*'Choices need to be made about what to do because you can't do it all' (FG 1).*

## 8. Topics to include in commissioning guidance for cancer rehabilitation

A significant amount of data was generated and there was some repetition of themes. The guidance should be available online and be clear and concise. It should have a combination of words and visual images to articulate key messages. The guidance needs language and terminology which gets everyone 'on the same page' about what cancer rehabilitation is, its scope and breadth and who is responsible. Key messages such as the holistic nature of rehabilitation and the fact that it crosses boundaries and straddles the entire pathway are needed.

*'Helping GPs understand what is cancer rehabilitation and what does it involve' (FG 1).*

*'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 is the loss of physical function, whether it is a psychological issue or just continuing education of their problem' (FG 3).*

The scope of the guidance has to be clear, e.g. is it dealing with all types of rehabilitation or just NHS services. Any distinctions between cancer rehabilitation and non-cancer rehabilitation have to be highlighted. Participants emphasised the importance of context setting and showing the scale of the problem with facts and figures.

*'Highlight the scale of the problem. Context, numbers, demographic bit' (FG 2).*

It is important to outline why commissioning cancer rehabilitation is important and the implications of not commissioning it. The economic arguments need to be central.

*'The minute you put in a document that if you had this service, you will reduce your bed days by this. You would reduce your bed expenditure by that. It makes people sit and think about it. And not those of us that are directly working on it. But the other people that are trying to juggle all of the priorities' (FG 3).*

Learning from, assimilating and building on previous work such as the AHP Commissioning Toolkit and the NHS England Commissioning Guidance is advised.

*'Having whole sets of different guidance, and reports, and bits and pieces, and actually, weaving them together. If someone can do that for you, it's really helpful. It makes it more usable' (FG 2).*

Highlighting the levers and drivers for rehabilitation is important and particular reference was made to STPs and managing cancer as a long-term condition.

*'So most of our... all of our SPG's in London, except for NCL, but we know that's going to change, have explicitly talked about living with cancer as a priority in the STP's and then most of them have talked about cancer as a long-term condition' (FG 1).*

Making clear links between cancer rehabilitation and the Recovery Package is recommended.

*'How does the commissioning guidance get them to understand what rehab means, in terms of integrated care, life after a cancer care review, you know' (FG 1).*

*'Showing GPs how to add quality to cancer care reviews' (FG 1).*

Showing links with other work streams and services such as smoking cessation, social prescribing and health checks was discussed, as well as implications for training of the wider workforce.

*'Guidance that links up the different bits, so it makes really clear how cancer rehabilitation fits in with everything else that's going on, to certainly cover recovery package interventions, and really making those clear links about where it's expected and how' (FG 1).*

*'There's something about where the professionals sit in there, who are delivering all sorts of services to cancer and non-cancer patients, and what they could do differently to support patients in the cancer journey' (FG 1).*

The guidance needs to clearly articulate what good commissioning looks like and who pays for what.

*'So if you had a point which was wherever it was, or wherever it occurred, which was rehab services, then people are going to be, if anything, if they are at all*

*thinking about this, they're going to be sat thinking, where does that start and who's paying for it? And that's going to be complicated by things like, well, is this specialised, or specialist .....people are going to look at it and the first thing they're going to say is, well, how complicated is that and do we have to... who's paying for it? Do we have to pay for it? (FG 1).*

It also needs a service specification to show what good rehabilitation looks like. Many features of a good rehabilitation service were discussed including collaborative commissioning, seamless pathways, cost effectiveness, a single point of access, care co-ordination and appropriate skill mix of staff. Achieving sustainability of services was a key message.

*'If our end point is to have a much more resilient rehab sustainable programme, pan London ultimately, or pan national from your point of view, we need to look at that. And if it's commissioned, it's... if it's established in that way, it'll be more protected' (FG 1).*

The guidance needs to reflect these features, and ensure that they can be commissioned. Best practice examples should be used and these should be sourced from across the country.

*'What makes a good rehabilitation service will be something that's self-sustaining, delivers, is responsive, doesn't necessarily require financial input from the patient, listens and is ongoing and so that if you then have got to your... you've been rehabilitated, you have the opportunity to return' (FG 3).*

*'If we have a centre of excellence that's in Manchester or Birmingham or Devon or whatever. I think we should know about it' (FG 3).*

Participants had mixed views about the use of local benchmarking data with the majority finding it important, but a few querying its benefit.

*'I think it's very important that people have an idea of how well they're doing in comparison to others' (FG 3)*

*'Because we can say as commissioners to our governing boards or so on, look, everybody is doing this except us. Why aren't we doing it?' (FG 3).*

*'Benchmarking doesn't always lead to an improvement in services' (FG 1).*

A directory of services would help both patients and professionals navigate the system, as the information is often not available.

*'In my cancer care reviews, I often have to find out for the patient. And I don't know enough about the local services that are available for them. Co-ordinating it, really' (FG 1).*

*'I think there are a lot of things out there. It's just a case of knowing what's the most recent information and who to turn to and what's going to be the right information and how detailed information' (FG 1).*

## **9. Topics not to include in commissioning guidance for cancer rehabilitation**

There were very few contributions here. One focus group suggested it is premature to think about this right now.

*'Too early to make a judgment' (FG 3) and 'We don't know what we don't know' (FG 3).*

Another group emphasised the importance of not presenting cancer rehabilitation as separate from other forms of rehabilitation.

*'I think it's quite important that the guidance doesn't come across as really separating out cancer rehabilitation and treating as probably a separate strand of work' (FG 2).*

*'Presenting cancer as separate costs more and causes a more disjointed system' (FG 2).*

## **10. Supporting implementation of guidance**

A wide range of issues was discussed here. Participants discussed how GPs find it difficult to keep abreast of new publications, and how using CCG communications teams would be the best way of publicising new guidance.

*'If you send this to our GPs, do you know what? None of them will read it. If you send it through us, and we have very good, very engaged communications team with our local population, at least I will know that they will open those e-mails' (FG 3).*

*'It would go to our communications people, that would then send out a covering type letter to say there is this new guidance, and it's available here, and have the link for us' (FG 1).*

Many participants suggested linking with Health and Wellbeing Boards and linking the guidance to STPs. In particular, being clear about how cancer rehabilitation can help support these plans over the next few years, although there is little about cancer rehabilitation in these plans.

*'It's about how we help CCGs and STPs to translate some of their ambitions, it'll probably be year two and year three though. It won't be year one' (FG 1).*



*'So as long as it was in our strategic directives, the implementation will be public 'cause we're accountable. For saying what we will promise to do' (FG 3).*

*'No confidence that there is sufficient detail within the STPs on cancer rehab' (FG 3).*

There is a need for collaborative, joined up commissioning, to work closely with local authorities and to show links between cancer rehabilitation and other services and professionals e.g. social prescribing and healthy lifestyles champions. Lessons need to be learned from the commissioning of others services such as diabetes, cardiovascular conditions and smoking cessation services.

*'So people quite readily commission smoking cessation services.. (FG 1).*

*'So it's very important, but in the mind of a financier, nothing, nothing beats people with diabetes. It just goes too far. It costs too much. It affects too many people' (FG 1).*

A clear message was given about how the entire system needs to be better educated about cancer rehabilitation. Information on the many benefits of cancer rehabilitation can help support implementation. Clear messages are needed about the economic benefits of cancer rehabilitation to incentivise the system.

*'All CCGs are financially challenged in one way or another' (FG 3).*

*'I think to start with rehab, a burning platform to make people do stuff is the money. It has to be the money and if we can't articulate that doing this better reduces admissions, it reduces length of stay, you haven't got a hope' (FG 1).*

*'Need to incentivise and help people to put this in place e.g. cancer waits still not being met' (FG 1).*

It was suggested that funders should be better educated about the services they are commissioning and that service visits could be helpful here, although they would have to be presented carefully.

*'Funders need to understand the area they are commissioning' (FG 1).*

*'What you need is a walk through that service, but it's... you've got to be very careful as you present it, so it can't be, we're going to rub your nose in it and show how, why you must do that' (FG 1)*

Clinical champions for rehabilitation are needed at all levels of the system, but particularly within primary care. Having high profile champions appears important but different areas will require different approaches.

*'We need an individual in each CCG passionate about cancer rehab' (FG 1).*

*'So, if we get the right level of support from primary care, it does come up the chain and there will be someone sitting in board meetings going, "Why have we not commissioned this service? What are you going to do about it?" (FG 2).*

*'Identify those who really care about this; and get them in conversation with the clinical directors, and make each other really unite the decision making process about what we should, and shouldn't commission' (FG 2).*

A final message was about access to services and how improvements in this aspect could help support implementation.

*'Funding has continued with IAPT because self-referral has worked so well' (FG 1).*

*'... the trick is to open it to all people who have the condition...as opposed to being only those with cancer being allowed to access' (FG 1).*

#### 4.4. Summary

The focus groups with commissioners have generated important and useful data for the future development of TCST commissioning guidance for cancer rehabilitation. There is significant overlap with findings from previous TCST work on commissioning guidance for lymphoedema services<sup>11</sup>, and also with work by NHS England on the commissioning of rehabilitation services<sup>1</sup>. It is clear that developing a sound economic argument for the development of cancer rehabilitation will be central to the development of future commissioning guidance.

Our findings suggest that cancer rehabilitation is poorly commissioned in London and this can leave services vulnerable and can have a considerable impact on patient care. There are multiple challenges including a lack of profile of cancer rehabilitation, significant gaps in services, workforce capacity issues and training needs, and a lack of knowledge about existing services. 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. There are a myriad of opportunities for improving cancer rehabilitation services in London through the STPs, the work of the Cancer Alliances and related workstreams such as the long-term conditions agenda.

Future guidance should include:

- A format that is accessible and uses visuals and words.
- Language which gets everyone 'on the same page' with respect to what we mean by cancer rehabilitation, its breadth, scope and interconnections with current strategic directives e.g. The Recovery Package.
- A clear economic argument for why rehabilitation is important and should be better commissioned.
- A clear outline of 'what good looks like' and how it should be commissioned, ideally using a service specification and examples of best practice.
- A focus on data and metrics to improve evaluation.

Implementation of the guidance will be complex and challenging but will be supported by linking the guidance to national directives and local priorities, having a good communications strategy and seeking local champions, across the system and at every level.

## 5. Conclusions and next steps

### 5.1. Summary of stakeholder engagement work

Triangulating data from the cancer rehabilitation task and finish group, the stakeholder engagement event and the focus groups with commissioners has provided clear and consistent messages around the issues and challenges with cancer rehabilitation, and how these can be tackled with commissioning guidance. Some work is still needed to clearly determine the scope of future guidance with respect to the overlap with mental health services. See Appendix 8 for an outline of the key findings from each engagement activity.

The key challenges that need to be addressed include:

- Economic: there are considerable opportunities to make cost savings through investment in cancer rehabilitation services but these are not always well recognised by commissioners.
- Profile/understanding of cancer rehabilitation: there is poor understanding of the scope and breadth of cancer rehabilitation, and the fact that it happens along and across every pathway of care.
- Current commissioning processes: this is not always done well for cancer rehabilitation and there is significant complexity and a lack of transparency in processes.
- Access to services: there are significant gaps in the provision of cancer rehabilitation services in London and evidence this is impacting on patient care.
- Workforce: there are shortages in the specialist rehabilitation workforce and significant education and training needs for the wider workforce.
- Data/metrics: there is a lack of data on cancer rehabilitation making it difficult to demonstrate value and impact.
- Changing demographics: an ageing population with increasing multi-morbidities mean there is an increasing complexity of need and a need to link better with other services e.g. those managing long term conditions or supporting self-management.
- System leadership: champions for cancer rehabilitation are needed at all levels of the system.

In conclusion:

- The commissioning of cancer rehabilitation in London is fragmented and poorly co-ordinated and this can leave services vulnerable and impact on patient care.
- There is an urgent need for commissioning guidance that is accessible and easy to use, develops a shared understanding of what good rehabilitation looks like and how it should be commissioned, provides a convincing economic case for 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. The cancer alliances and local champions will play a key role in helping drive this agenda forward.
- Implementation of the guidance will be complex and challenging but can be supported by linking cancer rehabilitation to national and regional directives e.g. The Recovery Package, stratified follow-up and integrated care, and local priorities, particularly STPs.

## 5.2. Next steps

The work plan that follows was endorsed by the Cancer Rehabilitation task and finish group in October 2016, ahead of a partnership application to Macmillan Cancer Support for additional funding for the Macmillan Rehabilitation Clinical Lead. Funding was approved in December 2016 and Dr Karen Robb will now be in post until December 2018. This funding enables a longer work programme and completion of comprehensive guidance and continued leadership activities within TCST, with a focus on cancer rehabilitation and consequences of treatment.

TCST will convene a multidisciplinary Steering Committee in March 2017 to oversee the work plan. The first priorities for the group will be to:

- Advise on the scope of the commissioning guidance, which will be ratified by the TCST Living With and Beyond Cancer Board
- Help determine clear timelines and deliverables for the project.

### 5.2.1 Work plan for 2017/18

#### 1. Produce commissioning guidance that builds on the findings from stakeholder engagement activities and will include:

- References to existing national specifications or best practice service specifications (where possible) with clear expectations on what cancer patients need from specialist and generic services (hospital, community, third sector) throughout the cancer treatment pathway, and includes a model of care for

cancer rehabilitation, so that all who commission have a clear outline of 'what good looks like'.

- Mapping of 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). TCST will require additional project support and support from the three Cancer Alliances to deliver this.
- Recommendations for service evaluations, quality assurance processes, patient experience measures.
- References to best practice patient information and support for self-management.
- Case studies.
- Recommendations for managing transition points between health, social care, third sector
- Inclusion of discussion on financial impact/assumptions where possible.
- Identification of key education and training needs, or best practice education standards for the workforce. TCST will require support from Macmillan, Health Education England and others to deliver this.

## **2. Develop a suite of tools to support commissioning of rehabilitation services, including:**

- Design of a cancer rehabilitation audit/benchmarking tool and support piloting of the tool. TCST require additional project support to complete this.
- Design of a workforce-modelling tool for cancer rehabilitation in conjunction with the Healthy London Partnership Workforce Programme, Health Education England and Macmillan. Then support the piloting of the tool. TCST require additional project support to complete this
- Develop sample business cases for commissioners for lymphoedema services and multidisciplinary cancer rehabilitation services and other tools to support commissioners (it is intended that tools will be identified based on future feedback).

## **3. Continue to provide system leadership on cancer rehabilitation by:**

- Establishing a stronger connection to the TCST Mental Health Task & Finish group e.g. some joint workshops/meetings to ensure the relevant interdependencies are identified
- Remapping lymphoedema services and evaluating the impact of TCST lymphoedema commissioning guidance. Update guidance where required.
- Providing support to STPs to facilitate implementation of recommendations from the commissioning guidance on cancer rehabilitation and to facilitate service improvements in cancer rehabilitation
- Engaging with local and national groups to continue to drive the cancer rehabilitation agenda forward.

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**Appendix 1: Membership of the Cancer Rehabilitation Task and Finish Group**

| <b>Role</b>   | <b>Organisation</b>                    | <b>Name</b>          |
|---|--|----------------------|
| Macmillan Rehabilitation Clinical Lead (Chair)  | TCST                                   | Dr Karen Robb        |
| Senior Strategy Lead, LWBC  | TCST                                   | Liz Price            |
| GP Advisor  | TCST                                   | Dr Martin Shelly     |
| 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   | Bart's Health NHS Trust                | Lindsay Farthing     |
| Macmillan Recovery Package Lead   | Barking, Havering and Redbridge        | Lucy Brooks          |
| Health and Wellbeing Manager  | Havering                               | Viki Bainsfair       |
| Dietetic Team Leader  | The Royal Marsden NHS Foundation Trust | Lucy Eldridge        |
| Community Head and Neck Team Lead   | Guys and St Thomas NHS Trust           | Samantha Tordesillas |
| Therapy Radiographer  | University College London Hospital     | Linda Harvey         |
| Principal Social Worker   | Royal Borough of Kingston              | Dawn Secker          |
| Clinical Lead Physiotherapist   | Marie Curie Hospice                    | Karen Turner         |

## Appendix 2: Attendance at the cancer rehabilitation stakeholder engagement event

### Stakeholder attendance per geographical area.

| <b>Geographical area</b> | <b>Number</b> |
|--------------------------|---------------|
| North East London        | 7             |
| South West London        | 7             |
| North Central London     | 3             |
| South East London        | 10            |
| Outer North London       | 5             |
| North West London        | 6             |
| Pan London/other         | 15            |
| <b>TOTAL</b>             | <b>53</b>     |

### Stakeholder attendance by stakeholder category.

| <b>Stakeholder category</b>             | <b>Number</b> |
|---|---------------|
| Provider                                | 32            |
| CCG commissioner                        | 2             |
| Service user                            | 4             |
| TCST (including commissioning managers) | 8             |
| Charitable sector                       | 5             |
| Other                                   | 2             |
| <b>TOTAL</b>                            | <b>53</b>     |



### Appendix 3: Cancer rehabilitation stakeholder engagement event programme



## Cancer Rehabilitation Consultation Event

**Date:** Wednesday 15<sup>th</sup> June 2016

**Time:** 09:30 – 15:30pm

**Venue:** Southwark Cathedral, London Bridge SE1 9DA

**Garry Weston Library**

*The aims of the event are:*

1. *To bring together a wide range of stakeholders to share knowledge and ideas around what good cancer rehabilitation looks like and how it should be delivered*
2. *To help shape Commissioning Guidance for Cancer Rehabilitation this will be led and developed by TCST over the next 5 months.*

*The day will combine presentations from service users, NHS England, Macmillan Cancer Support, TCST and the London region. There will also be facilitated table discussions and plenty of opportunities for networking. Refreshments will be throughout the day and lunch is also provided.*

|                 |  |
|-----------------|--|
| 9:30am          | <b>Registration &amp; refreshments</b>   |
| 10:00 – 11:30am | <b>Welcome from Chair</b><br><i>Liz Price, TCST</i>  |
|                 | <b>Keynote:</b><br><i>David Jillings, Service User</i><br>Table conversations:<br><i>Facilitated session with 8 groups (icebreaker, discuss what good practice looks like, provide examples)</i><br>Feedback from tables<br><i>Facilitators fast feedback from each group (2 mins/table)</i>             |
| 11:30 – 11:50am | <b>Refreshment break</b>   |
| 11:50 -12:45pm  | <b>Strategic overview for rehabilitation</b><br><i>Lindsey Hughes, NHS England</i><br><i>June Davis, Macmillan Cancer Support</i><br><i>Dr Karen Robb, TCST</i><br>Panel questions:<br><i>Lindsey, June, David, Karen</i>  |
| 12:45 -1:30pm   | <b>Lunch/networking</b>  |
| 1:30-3:25pm     | <b>Taking the strategy forward in London</b><br><i>Sharon Cavanagh, London Cancer and Julie Baker, SEL ACN</i><br>Table conversations:<br><i>Facilitated session with 8 groups and case studies (to help shape Guidance)</i><br>Feedback from tables<br><i>Facilitators fast feedback (2 mins/table)</i> |
| 3:25pm          | <b>Summary and Close</b><br><i>Chair: Liz Price, TCST</i>  |

Appendix 4: Data from engagement event ‘ice-breaker’ session: examples of good practice in cancer rehabilitation

| Table 1   | Table 2  | Table 3  | Table 4  | Table 5   | Table 6   | Table 7  |
|---|--|--|--|---|---|--|
| <ul style="list-style-type: none"> <li>Existing evidence – measuring outcomes</li> <li>In house dietitians: early intervention</li> <li>Recovery Package</li> <li>Specialist physio – prostate project at Bart’s, Stanmore Royal National Orthopaedic Hospital rehabilitation 10 year follow up</li> <li>Person specific/holistic/patient driven</li> <li>Motivational interviewing: training to be a facilitator for</li> <li>Time: appointment, relevant part of patient journey</li> <li>CNS/phase of rehabilitation appointment</li> <li>Prehabilitation</li> </ul> | <ul style="list-style-type: none"> <li>Focus on wellbeing: MDT, accessible, one stop shop. Plays to diverse skills of workforce and spans life course of user</li> <li>Focus on quality of life, ‘adding life to years’, quality of information (timely, accessible, simplified, systematic), family as part of process</li> <li>Need to put patient at the centre. What matters to them not to us.</li> <li>Co-ordination of care</li> <li>Common vision of rehabilitation</li> <li>Service examples include YMCA Thames gateway ‘Moving forward</li> </ul> | <p>Macmillan community oncology team in Havering:</p> <ul style="list-style-type: none"> <li>Takes referrals from small CNS team and GPs. Initial appointment is 1.5hrs, patient led, access to other services (social services, AHPs, hospice, psychology)</li> <li>Co-ordinates care, triages</li> <li>Holistic</li> <li>Signposting</li> <li>Early recognition of problems</li> <li>Improved quality and patient experience</li> <li>From patient viewpoint: more time, better informed, holistic, co-ordinated care, longitudinal relationships</li> <li>From provider viewpoint: early recognition, better</li> </ul> | <p>Glasgow CNS Team:</p> <ul style="list-style-type: none"> <li>Holistic needs assessment</li> <li>At beginning of pathway</li> <li>Community LA setting</li> <li>For service user confidence, re-assurance, availability</li> <li>For provider: MDT and holistic aspect</li> <li>For commissioner: leads to better self-management, patient in control, primary care involvement.</li> </ul> <p>Prostate discharge team Guy’s and St Thomas Hospital Trust,</p> <ul style="list-style-type: none"> <li>Planned into pathway</li> <li>Seminars after treatment, transfers to local community services and</li> </ul> | <ul style="list-style-type: none"> <li>Types of management dependant on certain patients, receptive with GPs, different services available</li> <li>Good example: Elderly Care Clinic: looks at elderly care and cancer care and streamlines care</li> <li>From patient viewpoint: has AHP appointment during pathway</li> <li>From commissioners viewpoint: treatment summary, UCLH working group</li> <li>Good examples at Guys and St Thomas: 4 cancer exercise classes, Joint AHP rehabilitation clinics, telephone rehabilitation clinic, dedicated</li> </ul> | <ul style="list-style-type: none"> <li>CHANT team, Guys and St Thomas: community head and neck rehabilitation team with AHPs and CNS, seamless care between GSTT and community, intensive rehabilitation, aims to reduce A&amp;E admissions, return to work, reduce antidepressant use, identify recurrence earlier, positive input on other LTC and healthy lifestyle</li> <li>INPUT St Thomas: pain management team: model for therapy, not a cancer service but takes referrals</li> <li>St George’s: outreach pilot service for H&amp;N,</li> </ul> | <ul style="list-style-type: none"> <li>Define pathway: what is expected? Compulsory. You have an appointment versus an offer</li> <li>Continuous co-ordination for patient centred care: team vs. single person, proactive not reactive</li> <li>Services that do well in palliative care: offer physical rehabilitation, dietetics, psychological support, include the whole family, can put interventions in place early, have AHPs as core, use Hospice UK guidance, pan London networks, good at innovation</li> <li>Survivorship groups in hospice: addresses fatigue, exercise and CBT used</li> </ul> |

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| <p>/rehabilitation as part of core service</p> <ul style="list-style-type: none"> <li>• Community based services/co-ordinated care out of hospital</li> <li>• Health and well-being events</li> <li>• Social prescribing/Bromley by Bow</li> <li>• Remote practices (innovation)</li> </ul> | <p>programme”; Hackney ACRT – co-ordinated care; AHP navigator role at Christie in Manchester; best practice in breast cancer is having access to a named CNS to help co-ordinate care; look at triborough CCGs commissioning for neurology (and neuro-oncology) and input on efficiency and productivity</p> | <p>planning for re-admission, re-referral, and better step down. From commissioner viewpoint: better co-ordination and signposting</p> | <p>voluntary sector</p> <ul style="list-style-type: none"> <li>• For provider: GP confidence</li> <li>• For commissioner: local pathway which is effective</li> <li>• For patient: control, access to education and information for themselves and their families.</li> </ul> <p>Wales<br/>Lymphoedema Service:</p> <ul style="list-style-type: none"> <li>• National strategy, parity of care</li> <li>• AHP national lead</li> <li>• Well evaluated</li> <li>• For service user: local services</li> <li>• For provider: networking</li> <li>• For commissioners: economic value</li> </ul> | <p>AHPs in certain tumour clinics to meet patient needs throughout the pathway</p> <ul style="list-style-type: none"> <li>• Good service models including MDT clinics with open door policy, screening for needs as an outpatient, specialist teams e.g. dietetics, lymphoedema</li> </ul> | <p>laryngectomy support group encourages patients to meet others</p> <ul style="list-style-type: none"> <li>• King’s Healthcare Partners: Acceptance and Commitment Therapy groups, addresses fear of recurrence, community and cross cutting across all tumour groups, 6 week course, 2.5hrs sessions, aims for reduced GP use, improved quality of life, support network</li> </ul> | <ul style="list-style-type: none"> <li>• Tottenham Hotspur Foundation offer cancer exercise programme</li> <li>• Use of volunteers: Hospice UK bid looking at training up volunteers to do home visits, motivation and buddying</li> </ul> |
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**Appendix 5: Data from engagement event case studies session: a summary of the key issues identified by participants**

| <b>B cell lymphoma: complex neurological rehabilitation</b>  | <b>Rectal cancer: post-operative rehabilitation</b>   | <b>Brain tumour: therapy and psychology interventions</b>  | <b>Breast cancer: physical activity scheme</b>  | <b>Lung cancer: in-patient rehabilitation</b>   | <b>Breast cancer: post-operative rehabilitation</b>   | <b>Laryngectomy: post treatment</b>   |
|--|---|--|---|---|---|---|
| <ul style="list-style-type: none"> <li>Staffing ratio for rehabilitation: nursing and AHP</li> <li>Lack of rehabilitation beds – neuro rehabilitation</li> <li>Change in attitude and ethos of care</li> <li>Ability to prioritise rehabilitation as a treatment</li> <li>‘Virtual ward’ initiatives</li> <li>Supporting palliative patients with rehabilitation</li> <li>Staff education; roles, patient goals, saving money, patient experience, staff experience</li> </ul> | <p>Areas of improvement:</p> <ul style="list-style-type: none"> <li>Knowledge of services – contacts, no central directory</li> <li>Standardised referral form/guidance</li> <li>Pain and fatigue management</li> <li>Physiotherapy</li> <li>Everyone should have</li> </ul> <p>Principles:</p> <ul style="list-style-type: none"> <li>Replicate other referral pathways i.e. stroke</li> <li>Service co-ordination</li> <li>Recognising importance of buy-in from seniors</li> <li>Seamless service –</li> </ul> | <p>Improvements:</p> <ul style="list-style-type: none"> <li>Treatment or care plan summary</li> <li>Support for husband</li> <li>Relationship building with primary care</li> <li>Unnecessary decline in function can be prevented</li> </ul> <p>Commissioning:</p> <ul style="list-style-type: none"> <li>Data collection to drive change. Evaluation/evidence</li> <li>Bigger primary care units/join up</li> <li>Shared access to records from secondary/primary/social services/</li> <li>Case management role/key worker in primary care</li> <li>Learn from others who have co-ordinated care and avoided admissions e.g. early supported</li> </ul> | <ul style="list-style-type: none"> <li>What do commissioners need to know</li> <li>Move away from a cheap leaflet</li> <li>Move to prehabilitation: pre op sessions with physio and breast care nurse, pre assessment clinic. Exercise demonstrations. Clear and concise exercise plan.</li> <li>Move away from medical jargon</li> <li>Invest in quality</li> <li>Not a one size fits all model</li> <li>Mental health issues just as important as rehabilitation for surgery</li> <li>More than just rehabilitation,</li> </ul> | <ul style="list-style-type: none"> <li>Poor understanding of side effects and quality of life goals, length of life</li> <li>Uniprofessional working model</li> <li>Demystification of cancer diagnosis</li> <li>Local management of fatigue</li> <li>Changing clinical speciality job planning, role in upskilling generalists</li> <li>Transport, aging population with co-morbidities</li> <li>Generic assessment – use of HNA to inform rehabilitation priorities</li> <li>Defined pathway</li> </ul> | <p>Improvements needed:</p> <ul style="list-style-type: none"> <li>Pre-op physio input: exercise and advice /could be in a group, includes support</li> <li>Written info not enough</li> <li>Could be band 4 physio technician like the ‘joint school’ in orthopaedics</li> <li>Specialist staff can then develop exercises or do more specialist work</li> <li>Screening programme pre-op with a screening protocol</li> <li>AHPs involvement in MDTS: would be good to have pre knowledge of patients</li> <li>Key-worker/navigator needed to monitor care is co-ordinated</li> </ul> | <p>Improvements needed:</p> <ul style="list-style-type: none"> <li>Community rehabilitation team at beginning of the pathway: level 4,3 and level 2 support</li> <li>Stoma nurse trained up</li> <li>Train patient to develop GP relationship for long-term</li> <li>Access to commissioner</li> <li>Email correspondence</li> </ul> <p>Key principles:</p> <ul style="list-style-type: none"> <li>Increase awareness of AHP role/patient experience</li> <li>Increase awareness of AHP cost savings: decrease length of stay, admission</li> </ul> |

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|  | <p>health/social, acute/ community</p> | <p>discharge</p> <ul style="list-style-type: none"> <li>• Medical needs can be specialist but functional needs can be generic.</li> </ul> | <p>include needs of family</p> <ul style="list-style-type: none"> <li>• Compassion fatigue in rehab professionals: level 2 clinical supervision training</li> <li>• Rehabilitation needs to be home/community based with joined up thinking; re-introduce home visits</li> <li>• Join up cardiac, stroke, cancer care</li> </ul> | <ul style="list-style-type: none"> <li>• IT implications</li> </ul> | <ul style="list-style-type: none"> <li>• Access to health and well being services, charity sector</li> <li>• Pathway for referrals</li> </ul> <p>Key principles:</p> <ul style="list-style-type: none"> <li>• Cancer trained AHP to do prehabilitation: screening by band 4, identify risk, psychological issues, lymphoedema, work/vocational needs, pre morbidities. Breast cancer needs prehabilitation but other cancers could be post</li> <li>• Signposting needed</li> <li>• Includes self-management /could be band 4/could be group setting/telephone clinics</li> <li>• Outcomes: early intervention/decrease length of stay; addressing unmet need</li> <li>• Treatment should be based on need not new patient/follow up ratios</li> </ul> | <p>prevention</p> <ul style="list-style-type: none"> <li>• Upskill/educate level 1 SALTs and other AHPs.</li> </ul> |
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## Appendix 6: Engagement event: actions and challenges from 'post-it' notes

| ACTIONS  | CHALLENGES  |
|--|---|
| <ul style="list-style-type: none"> <li>• AHPs need to take students to increase exposure to oncology</li> <li>• Recommendations needed on core outcome sets as part of commissioning guidance</li> <li>• Get patient groups activated</li> <li>• Collect data (quantitative and qualitative)</li> <li>• Raise gaps</li> <li>• Tariffs for rehabilitation</li> <li>• Tariff: how do rehabilitation services, including Health and wellbeing events, get paid for</li> <li>• Tariff: case examples today require radically different degrees of rehabilitation so needs to be taken into account when negotiating rehabilitation tariff</li> <li>• Better co-ordination with voluntary sector/cancer charities</li> <li>• Forum for linking and contributing resources pan London and advertise this to AHPs</li> <li>• Central resource area for sharing case studies, new roles, publishing useful information for others such as an NHS network for cancer rehabilitation</li> <li>• Address London Cancer data re: lack of AHP resource and general understaffing of AHPs across London – a big issue!</li> <li>• Prehabilitation - for patients needing surgery but not fit for surgery because of e.g. excessively overweight. Don't re-invent the wheel e.g. enhanced recovery programme. Preparation for surgery for all</li> <li>• More commissioning/ business case training or awareness training for lower bandings so their ideas can be developed</li> <li>• There needs to be more AHP involvement in Government working parties e.g. independent cancer taskforce. Our colleges need to be involved</li> <li>• Better communication re: advertising events for AHPs and</li> </ul> | <ul style="list-style-type: none"> <li>• Time for high band clinicians to lead as well alongside providing clinical expertise</li> <li>• Linking our current services together and knowing what is out there already for all cancer professionals and service users</li> <li>• Temel et al 2010, Early intervention palliative care = increased survival time therefore what does palliative have that is the success?</li> <li>• Changing culture, treatment does not stop, rehabilitation is the beginning.</li> <li>• Getting AHPs to see that working in the community benefits patients</li> <li>• Compassion fatigue</li> <li>• Staff morale/sickness affects patient care</li> <li>• How to properly evaluate existing successful services. We need strong evidence of effectiveness of services to inform the development of new business cases/services</li> <li>• Lack of resource</li> <li>• Recruitment into rehabilitation problems</li> <li>• Low workforce</li> <li>• Integrating rehabilitation throughout treatment pathway</li> <li>• Psychological support in rehabilitation setting</li> <li>• Prehabilitation for patients</li> <li>• Growing patient numbers</li> <li>• What models inform rehabilitation and change? How does the above organise service delivery and cultural change?</li> <li>• Concern that rehabilitation and other pathways will not communicate leading to fragmented delivery and commissioning</li> <li>• Ability of primary care provider units to have sufficient skill mix and roles. Need to be much larger units/practices.</li> <li>• Palliative Care rehabilitation = the transformation of the dying into the living, the restoration of a patient to a person (Oxford textbook of palliative medicine)</li> </ul> |

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| <p>professionals to attend; no SALT on 'Commissioning Guidance for Rehabilitation' representation</p> <ul style="list-style-type: none"> <li>• Staff and patients need to be central in strategy as this is the relationship of help</li> <li>• Psychological resource needs to be seen as part of AHP, and embedded within service delivery. This will impact and create cultural change i.e. body mind integrated. Diversity of approach will enhance effectiveness</li> <li>• Look at cardiac rehabilitation and pulmonary rehabilitation, routine exercise classes. And stroke rehabilitation, if you have a stroke, you see a physiotherapist within 24hrs as routine</li> <li>• Please don't develop guidelines in isolation from other LTCs</li> <li>• Use keyworkers</li> </ul> | <ul style="list-style-type: none"> <li>• Need to have a germinate, integrated MDT approach to rehabilitation, incorporating the psychological, with no professional model dominating</li> <li>• Is cancer rehabilitation work fully acknowledging the generic as well as specialist, balance needed?</li> <li>• Some of speakers come across as protectors of their AHP profession rather than person-centred rehabilitation needs</li> <li>• Patient Reported Outcome Measures</li> <li>• Financial incentives</li> <li>• Getting Trust Board awareness</li> <li>• Increasing GP site specific knowledge and accessing those with specialist interests to help improve survivorship of patients in the community and increase patient support and access to services</li> <li>• Lack of robust measurement of services in terms of outcomes and outputs. In current climate these need to be financial as quality is expected along with patient experience. Improvement in financial e.g. reduced outpatient attendances, decreased length of stay, anything else would be really helpful</li> <li>• Are we really linking and learning as much as we can/need to from generic long term conditions (LTC) work e.g. re: House of Care, Patient activation, Care Planning, micro commissioning, system changes</li> <li>• If the Recovery Package is working well (and as intended) the HNA is simply an 'agenda setting' part of a collaborative care planning conversation, not an end in itself. Shouldn't we work on getting that right, in which case people would get the referral to what they need at that point in time, rather than creating another cancer improvement 'industry' of generic LTC models</li> <li>• Trying to trial/pilot new innovative services within existing, already pushed services</li> </ul> |
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## Appendix 7: Format of focus groups

### Scene setting:

- Discuss our roles and summarise interconnections with Macmillan and TCST workstreams
- Explain purpose of focus groups
- Outline format of focus group and get written consent for audio recording
- Ensure understanding and answer any questions.

### Themes to be explored and example questions within each theme:

#### **1. *Understanding of the scope and breadth of (Cancer) Rehabilitation***

- What do you understand by rehabilitation and rehabilitation for those with cancer?
- Can you give any examples of good (cancer or non-cancer) rehabilitation services you know

#### **2. *How rehabilitation services for people living with and beyond cancer are currently commissioned***

- How are rehabilitation services for those with cancer commissioned in your area?
- How do you decide what to commission, what factors are important?
- What do you think are the gaps in rehabilitation services for those with cancer?
- What (qualitative and quantitative) data, if any, is collected locally about rehabilitation services delivered for those with cancer?

#### **3. *Improving the commissioning of these services?***

- What are your views on the recent HLP Commissioning Guidance for Lymphoedema? Is it helpful? Is there anything you do not like about it?  
[https://www.myhealth.london.nhs.uk/system/files/Commissioning\\_guidance\\_lymphoedema\\_FINALAug16%20%282%29.pdf](https://www.myhealth.london.nhs.uk/system/files/Commissioning_guidance_lymphoedema_FINALAug16%20%282%29.pdf)
- What would you like to see included in the cancer rehabilitation commissioning guidance?
- Is there anything that you would not like to see included?

#### **4. *Implementation of the guidance***

- What would help support the implementation of the commissioning guidance?
- How do you see Commissioning Guidance for cancer rehabilitation being used and implemented?



**Appendix 8: Summary of engagement activity**

| <b>Cancer Rehabilitation Task and Finish Group</b>  | <b>Stakeholder engagement event</b>  | <b>Focus groups</b>   |
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| <p>Issues raised by the group included funding challenges, gaps in services and multiple unmet needs across many tumour groups, lack of knowledge and awareness of cancer rehabilitation in the wider system, lack of sufficient care throughout the entire pathway, workforce training needs, lack of sharing/dissemination of good practice and good practice models, insufficient good data on rehabilitation services.</p> <p>Some questions remain outstanding around the scope of future commissioning guidance, particularly the overlap with mental health and some aspects of the management of consequences of treatment e.g. psychosexual health i.e. are they within scope?</p> | <p>Key findings from the day were:</p> <ul style="list-style-type: none"> <li>• The timing, quality and quantity of information is important when preparing patients for consequences of treatment, and this is not always done well.</li> <li>• Participants’ descriptions of good rehabilitation services during the icebreaker session are consistent with those described in previous work by NCAT and NHS England. Findings fall under 4 main themes: co-ordination of services, quality and timing of care, workforce and evaluation of services.</li> <li>• These themes were reflected again in the ‘case studies session’ and in the ‘challenges for rehabilitation’ displayed on post-it notes. An additional theme around awareness and understanding of rehabilitation was also discussed.</li> <li>• The actions suggested by stakeholders on ‘post-it’ notes related to improving quality of services, improving profile and awareness of rehabilitation, improving the funding of services, workforce education and training and service user engagement. These can all be addressed in future commissioning guidance.</li> </ul> | <p>Findings suggest that cancer rehabilitation is poorly commissioned and this can leave services vulnerable and impact on patient care. There are significant gaps in services and lack of knowledge about existing services. Lack of data on cancer rehabilitation makes it difficult to demonstrate the impact and benefits of services. There are myriad opportunities within the current health and social care system including the STPs and the long-term conditions agenda.</p> <p>The main considerations for future guidance appear to be:</p> <ul style="list-style-type: none"> <li>• A format that is accessible and uses visuals and words.</li> <li>• Language which gets everyone ‘on the same page’ with respect to what we mean by cancer rehabilitation, its breadth, scope and interconnections with current strategic directives.</li> <li>• A clear economic argument for why rehabilitation is important and should be better commissioned.</li> <li>• Benchmarking data with local relevance.</li> <li>• A clear outline of ‘what good looks like’ and how it should be commissioned; ideally using a service specification.</li> </ul> <p>Implementation of the guidance will be complex and challenging but will be supported by linking the guidance to national directives and local priorities, having a good communications strategy and seeking local champions, across the system and at every level.</p> |