Service Improvement Tools for Cancer Rehabilitation

Transforming Cancer Services Team for London

Living With and Beyond Cancer Team

December 2018

Contents

This report was prepared by Healthy London Partnership

The Transforming Cancer Services Team (TCST) are part of Healthy London Partnership, formed in 2015. Our aim is to make London the healthiest global city by working with partners to improve Londoners' health and wellbeing so everyone can live healthier lives.

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

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

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Being told 'you have cancer' can affect so much more than your health – it can also affect your family, your job, even your ability to pay the bills. But you're still you. We get that. And, after over 100 years of helping people through cancer, we get what's most important: that you're treated as a person, not just a patient.

It's why we'll take the time to understand you and all that matters to you, so we can help you get the support you need to take care of your health, protect your personal relationships and deal with money and work worries.

We're here to help you find your best way through from the moment of diagnosis, so you're able to live life as fully as you can. For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk

Acknowledgements

TCST would like to thank the Task and Finish Group for their time and effort:

- Georgina Wiley (project lead) – Macmillan Project Facilitator, Transforming Cancer Services Team for London
- Vanessa Brown – Senior Macmillan Project Manager - Living with and beyond Cancer, RM Partners.
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- David Jillings - Trustee, the Pelvic Radiation Disease Association
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- Karen Turner - Oncology Therapy Service Lead & Clinical Specialist Physiotherapist, Royal Free London NHS Foundation Trust & Marie Curie Hospice, Hampstead.

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Executive summary

The TCST Service improvement tools have been developed through extensive stakeholder engagement and evidence building activities.

The user voice has been at the heart of this work. The tools outline a clear framework for what good cancer rehabilitation looks like and what service components are needed for proactive, personalised, accessible and coordinated care to be delivered. The tools were well received by providers and thought to have a range of uses including raising the profile of rehabilitation services with senior managers, engaging with commissioners, undertaking service development activities and demonstrating patient centred care.

In 2016 the Transforming Cancer Services Team (TCST) undertook a scoping project to better understand cancer rehabilitation services in London. Recommendations around the need for comprehensive commissioning guidance included a suite of resources to support commissioning, one of which is a cancer rehabilitation benchmarking/service improvement tool.

A steering committee was set up to oversee the work, and three task and finish (T&F) groups were formed including one to focus on the tool. As part of the development of the tool, two consultation events were held, one aimed at service users and one at service providers. Each event sought to understand the essential aspects of service delivery, the themes which should be included in the tool, and how it should be utilised. In addition, a range of key documents were considered.

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

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

Key themes from the events included:

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

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

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

In addition, providers felt the tools would give an opportunity to improve patient care and experience, build the evidence base for service development, and facilitate thinking time to focus on team objectives. They also wanted the opportunity to be able to benchmark themselves

against other services. The tools were piloted in London across a range of cancer rehabilitation services and refined for relevance and usability before being finalised.

The patient voice has been at the heart of this work, and TCST believes that these innovative multifaceted tools have implications across the rehabilitation sector as part of quality improvement activity for providers, as well as supporting quality assurance for commissioners.

Benefits for Commissioners

The tools:

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

Benefits for Service Providers

The tools:

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

Benefits for Service Users

The tools:

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

Recommendations

1. Embed the service improvement tools into clinical practice. This will require endorsement from CCGs, STPs, Alliances and continued support from TCST for implementation.
2. Cancer rehabilitation services to meet with senior managers/local commissioners to speak about their experiences with the tools, and about service improvement opportunities they have identified through the process
3. As a next phase of this work, the tools could be used to allow benchmarking between services. This would require infrastructure that can support this, such as the NHS Improvement Model Hospital.

Next Steps

1. TCST will work with Macmillan Cancer Support to launch the tools together with the report on the Macmillan Cancer Support website, alongside a communications plan and evaluation framework (Dec 2018)
2. TCST will refine the tools following a 6-month evaluation period (June 2018)
3. TCST will use findings from this work to inform the TCST Commissioning Guidance for Cancer Rehabilitation due April 2019
4. TCST will continue discussions with Macmillan Cancer Support and partner organisations to support benchmarking activities across services.

Background

In 2016 the Transforming Cancer Services Team (TCST) for London undertook a project 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. The outcome of this project was the TCST report: *Cancer rehabilitation: a scoping report for London.* This report highlighted that there were significant gaps in cancer rehabilitation services and the rehabilitation workforce across London, and evidenced that this impacts on patient care. There were clear recommendations to develop a suite of tools to support commissioning of rehabilitation services, including the design and piloting of a cancer rehabilitation service improvement tool.

Following further funding from Macmillan Cancer Support to cover the period until March 2019, a new multidisciplinary Cancer Rehabilitation Steering Committee was formed, chaired by Dr Karen Robb (KR), to oversee the work plan. The priority for the steering committee was to finalise the scope of future commissioning guidance and oversee the work and timelines for deliverables. Three T&F groups were established to work on mapping of cancer rehabilitation services, development of a minimum dataset for cancer rehabilitation, and development of a service improvement tool. Decisions were ratified by the pan London Living With and Beyond Cancer (LWBC) Partnership Board and endorsed by the London Cancer Commissioning Board.

As background to this piece of work between November 2014 and March 2015 the four NHS England Regional Rehabilitation Leads (RRLs) undertook a project to collate information on how well, and how easily, local rehabilitation services could benchmark themselves against the 'Principles and Expectations for Good Adult Rehabilitation' (written to reflect a provider's perspective), as provided in the NHS report 'Rehabilitation is everyone's business: Principles and expectations for good adult rehabilitation'. The findings from this work suggested that with refinement, the template tool used by the RRLs could be a useful tool for future benchmarking but also that the 'Expectations of good rehabilitation' were important to capture as they focused on service users' views and what matters most to them. Both the Principles and Expectations of Good Adult Rehabilitation are documented here and within the Commissioning Guidance for Rehabilitation (pages 31-35). With this in mind, TCST considered the patient voice as integral to the development of our service improvement tools.

Purpose

The purpose of this document is to:

- Provide an overview of the development and piloting of TCST service improvement tools for cancer rehabilitation services
- Provide recommendations on how these tools could be used by providers, commissioners and others
- Outline the next steps for this work.

Aim

The aim of this work was to develop and pilot a service improvement tool to support providers, commissioners and others in delivering high quality cancer rehabilitation services.

Objectives

- Bring together a Task and Finish (T&F) group from members of the TCST Cancer Rehabilitation Steering Committee to complete the project.
- Design a tool utilising learnings from the benchmarking tool developed by NHS England, as outlined in the NHS report ‘Rehabilitation is everyone’s business: Principles and expectations for good adult rehabilitation’
- Support piloting of the tool across London
- Incorporate learnings and feedback from pilot sites
- Produce final report including final version of the tool.

Key Stakeholders

- CCGs and STPs
- NHS arm length bodies
- Macmillan Cancer Support
- Cancer Alliances
- Acute, community and primary care providers
- Third Sector Parties
- Service Users

Producing the Tools

1. Overview

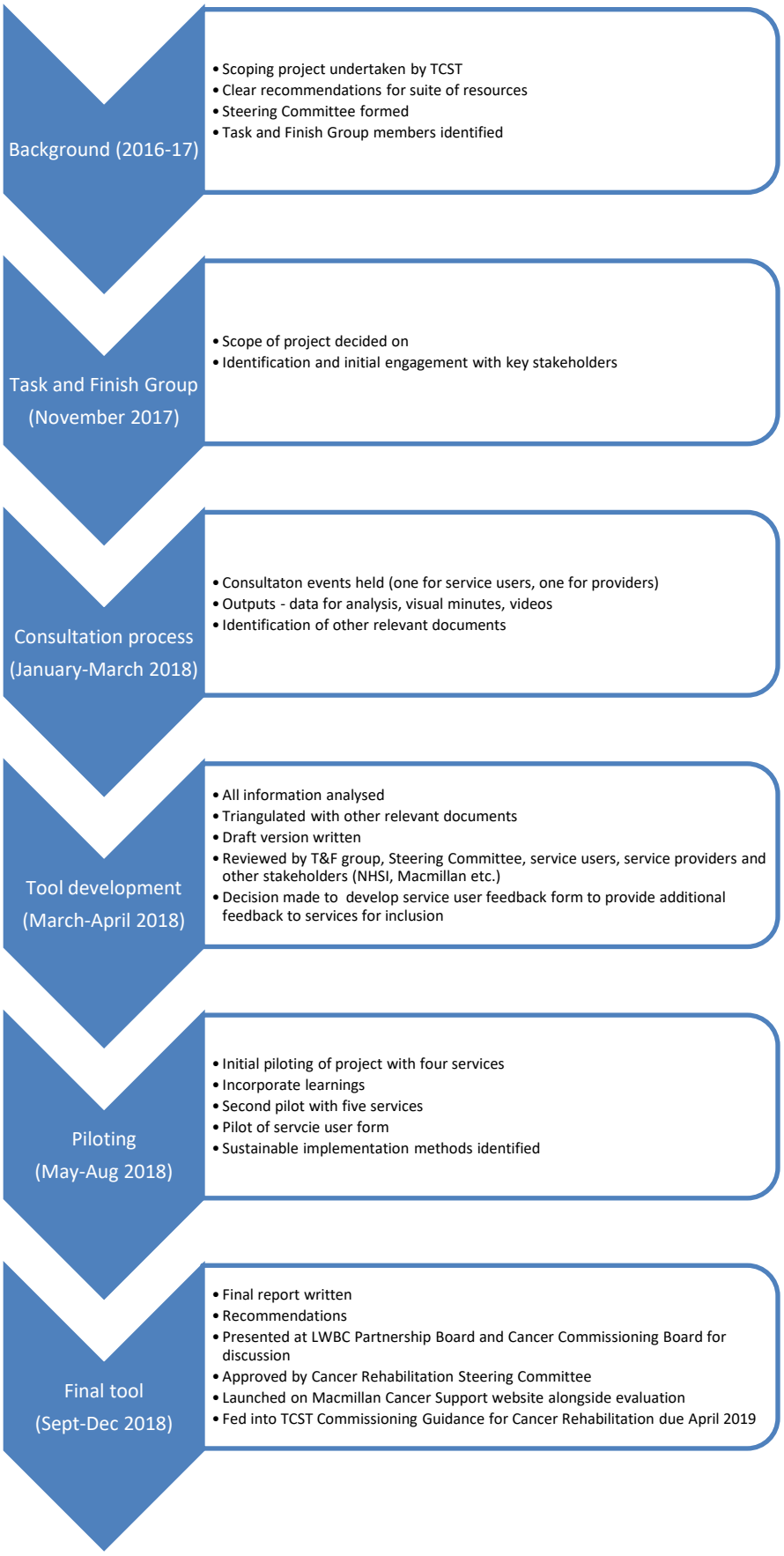
A Task and Finish group (T&F group) was brought together from the TCST Cancer Rehabilitation Steering Committee. The group was chaired by Georgina Wiley (Macmillan Living With and Beyond Cancer Project Facilitator) and met regularly throughout the project via face-to-face meetings and teleconferences. There was also regular email correspondence. There was a consensus that any tool should initially be used as a way for services to examine their current delivery, and start conversations about identified areas for improvement. Future work could allow services to measure themselves against others i.e. benchmarking activity.

The T&F group felt strongly that the tools should:

- Have clinical relevance and utility to be of significant benefit to services
- Be iterative and easily embedded into clinical practice
- Be applicable to all services (e.g. acute/primary/community)
- Include areas that are important to patients and carers to have meaning to patients and carers
- Provide a learning and development opportunity for AHPs and others
- Provide practical support to commissioners.

The T&F group consulted with service users, service providers and commissioners to ensure the tool was a representative of what the sector and its users wanted. There was also recognition that any tool developed should be initially marketed as a service improvement tool, not a benchmarking tool.

Figure 1: Overview of project



2. Service User Consultation Event

A consultation event was held on 17 January 2018 for service users and carers. All attendees signed consent forms to be recorded, photographed and filmed.

The event was well-attended and provided essential input into the development of the service improvement tool from a user perspective. Findings from the event align well with the expectations of good rehabilitation as set out by NHS England in the document 'Principles and Expectations of Good Rehabilitation'.

Attendees

21 people completed the pre-event survey monkey. 18 service users attended the event. Of these 14 were service users (either current or past patients), 3 were carers and one was an interested member of the public who had seen the event advertised on Eventbrite. The majority (n=16) were aged over 50 and there were more females than males.

All patients had accessed a number of cancer rehabilitation services:

- Physiotherapy 7 (35.0%)
- Speech and Language Therapist 3 (15.0%)
- Dietetics 12 (60.0%)
- Occupational Therapy 3 (15.0%)
- Group classes focused on cancer rehab (exercise etc.) 3 (15.0%)
- Lymphoedema service 4 (20.0%)
- Psychology or counselling 8 (40.0%)
- Pain service 5 (25.0%)
- Social work 2 (10.0%)
- Other: acupuncture

The Event

Members of the Task and Finish group facilitated the event. The afternoon was divided into two sessions. The group were firstly asked to write their responses to the following questions on Post-it notes. These were then discussed by the group.

- What matters most to me about cancer rehabilitation?
- What would a 5-star cancer rehabilitation service look like?
- What has or hasn't worked in a cancer rehabilitation service?
- What do you wish you had known at the time that you know now?

Media

In addition to the above activities a visual minute taker from Creative Connection attended *(Figure 2).*

Several short film clips were also produced from the day. Attendees also had the opportunity to have their photo taken with a message board.

Both the video clips and photos will be used to promote the importance of cancer rehabilitation.

Results

All the information collected on the day was thematically analysed by GW and subsequently reviewed and corroborated by a second member of the T&F group (AS). Both assessors were experienced in content analysis. A number of key themes were identified as central to development of the tool and these were:

1. Services involve the patient, are outcome/goal focused and incorporate holistic care

- **Individualised service** which **involves the patient** in both decision making and planning.
- Is **outcome/goal focused** and considers the patient **holistically**, not just in the context of their cancer diagnosis.
- Incorporates **practical support**.
- **Ensures service users are aware of what is going to happen**
- Identifies **what rehabilitation services are available** to them

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

"We don't just want to survive."

2. Services are accessible and timely

- **Easily** consistently **accessible to all**
- **Available at the time** in the pathway **when needed**
- E**nough time is allocated** in appointments,
- **Look at the whole pathway of care** and allow access to **long-term rehabilitation** if needed
- **Good signposting** into and out of the service (including knowledge of available services)

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

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

3. Care is coordinated and there is good communication between the MDT and to the patient

- **Consistent coordinated care** with **good communication between the whole MDT** (including the patient). Regular updates provided to the patient's GP
- Makes sure the **patient is aware of what is happening and will happen,** including the potential need for cancer rehabilitation and **what services are available**
- **Harmonisation** of various care management services: a **'One Stop Shop'** – the ability to visit and see all health professionals required at one time

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

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

4. *Care is compassionate, supportive and understanding*

- Staff take the time to provide care that goes beyond the technical definition of their professional discipline. **Care given is always compassionate, supportive and understanding**

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

5. *Staff are adequately trained to provide specialist care*

- Service is provided by **trained professionals** who can provide **specialised and expert care**

"A skilled, adaptable workforce that has the capacity to deliver good rehabilitation services."

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

6. *Incorporates access to others who have had a similar experience*

- Allows access to those who are also experiencing or have experienced cancer. Allows space for and **recognises the importance of a peer support network**

"Having participants in the service who have had a similar treatment."

"Opportunities to share experiences with others."

7. *Services are available to families – recognising that a cancer diagnosis not only affects the person with cancer*

- Recognises that cancer is **not a solo experience** – **family and loved ones are also affected**

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

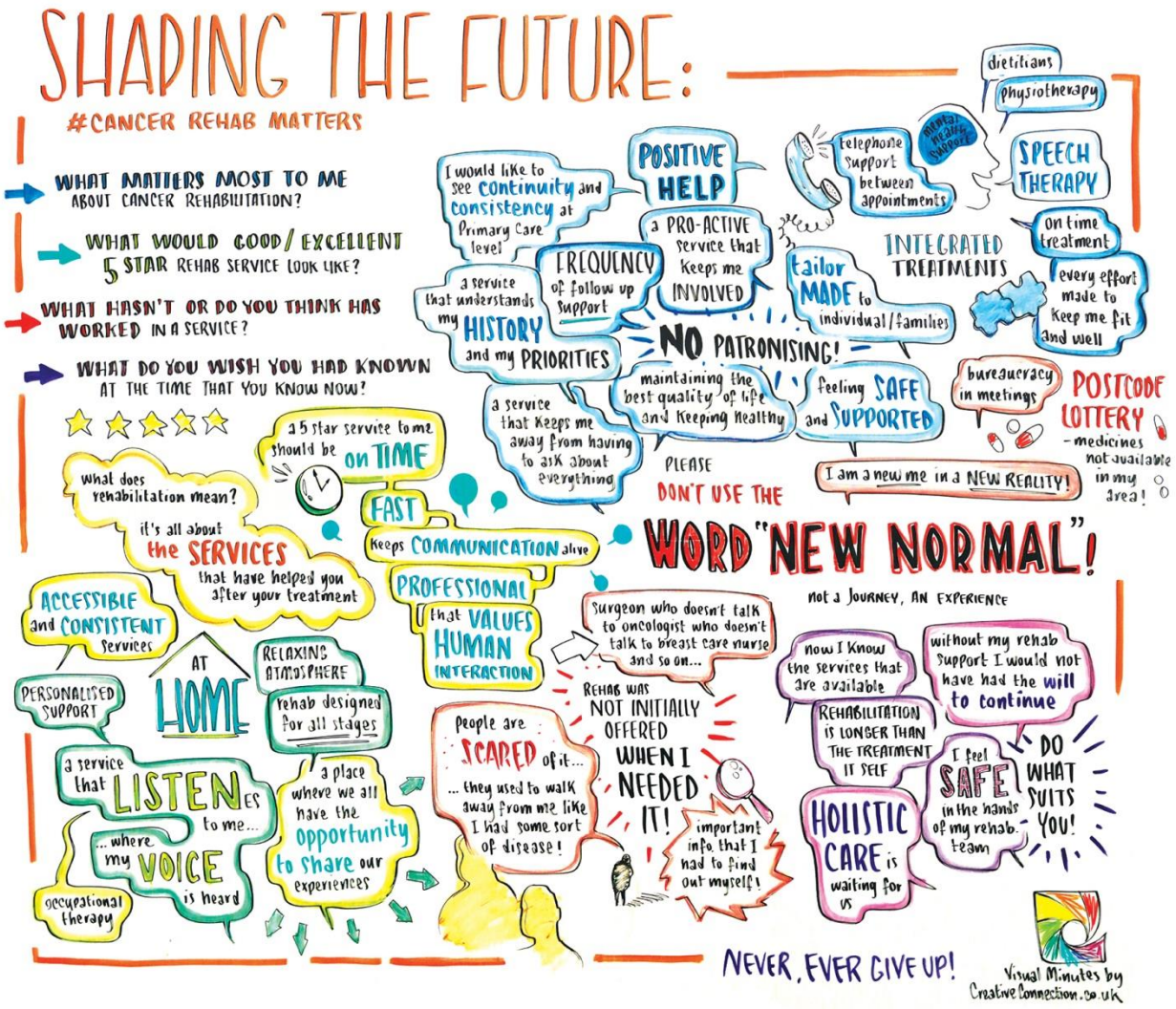
8. *Sufficient resources are available to allow the development of services as well as on-going provision*

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

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

A summary of themes is located in Appendix E. Many of these are also reflected in the mural of the day, see *Figure. 2.*

Figure 2: Mural representing the key discussions at the event



3. Service provider consultation event

Overview

A consultation event was held on 16 June 2018 for service providers. 18 people attended the event, representing a range of clinical services and professional backgrounds, including service managers project managers. Two attendees worked in private practice, with the rest working for the NHS.

Sessions

The event was divided into two sessions. Session one used similar questions to those asked during the first event with service users, with data collected on Post-it notes:

- What do you see as the key elements of the cancer rehabilitation service you are providing? (If you are not providing a service what do you think are the important elements?). Consider this question from the perspective of both care-giving as well as service operations
- What do you think is important to service users about a cancer rehabilitation service?
- What are the attributes of a gold star service?
- What do you see as current barriers to care?

Participants were then divided into four groups and asked to characterise the responses from the Post-it notes into themes. These themes were then discussed by the wider group.

The second session focused on the tool itself. Attendees were asked the following questions in a plenary group discussion:

- What is the purpose of a benchmarking/service improvement tool?
- What are the benefits of a tool and how would you use it?
- What are the barriers and do you think you would use it?
- What other information should we collect?

Results

Following the event all of the information collected on the day was thematically analysed by the project lead with support of the T&F group.

Session One
Overall responses to the four questions fell in the following categories: Operation of the service, coordination of care (including accessibility), patient experience and staffing. An overview of the themes is shown in Table 1 and a summary of the raw data is shown in Appendix F.

Session Two
A summary of the key themes of the discussions on the tool is also shown in Table 1.

Table 1: Key themes from service provider event analysis

Session 1	Session 2
Key elements of a cancer rehabilitation service Answers related to accessibility (easy access points at all points along patient cancer journey and services being in an accessible location), having coordinated and integrated care, which involves the MDT and is provided by specialists, incorporating symptom control and management, and is adequately resourced What is important to service users? The themes with the most responses related directly to accessibility, followed by good communication between the whole MDT (including the patient) and care coordination Attributes of a gold star service The themes with the most mentions related to accessibility (both availability and equality of access to services) and coordination of care Barriers to care Overwhelmingly, lack of resources was mentioned by attendees relating to equipment, staff and funding. Other sub-themes included lack of equity in provision of care, long waiting lists and poor awareness of services and what they do	Purpose of the benchmarking/service improvement tool Participants were asked to identify what they felt the purpose of a benchmarking/service improvement tool would be for themselves, their service and the wider health system Key themes identified were: • Opportunity to identify gaps in service • Opportunity to develop common standards (of care)/provide guidance to build/start service • Opportunity for reflection time • Opportunity to see the service as a whole (know what is happening with other services and how these work together) • Provide evidence to educate others about importance of cancer rehabilitation • Opportunity to see what others are doing (benchmarking against other services) • Help to develop cases for commissioning services/ advocate what is needed Benefits of a benchmarking/service improvement tool/how it would be used Participants were asked to identify the benefits of the tool and how they would use it in their own practice. Key themes included: • Evidence to back up service development • Improving patient care • Opportunity to benchmark against other services • Driving innovation and new ways of doing things • Building an evidence base

4. Tool content development process

As outlined earlier in this report, it was agreed that two tools would be produced; a comprehensive tool to be used by service providers, and a second shorter tool to be used by service users. Development of the tools was an iterative process with review and feedback from a number of key stakeholders including:

- The wider TCST team
- The TCST Cancer Rehabilitation Steering Committee
- The London Living With and Beyond Cancer (LWBC) partnership Group
- Service users
- Service providers
- Commissioners
- Macmillan Cancer Support
- NHS Improvement (AHP Professional Lead, Workforce Productivity)

Themes generated from the consultation events were triangulated with relevant resources to ensure that all key aspects of cancer rehabilitation were included in the tools.

Relevant resources:

- NHS England (2015): 'Rehabilitation is everyone's business: Principles and expectations for good adult rehabilitation' https://www.networks.nhs.uk/nhs-networks/clinical-commissioning-community/documents/principles-and-expectations
- Macmillan Cancer Support (2017): 'Allied Health Competence Framework for Professionals working with people affected by cancer' https://www.macmillan.org.uk/_images/allied-health-professions-framework_tcm9-314735.pdf
- NHS England (2015): 'Culture of Care Barometer' https://www.england.nhs.uk/wp-content/uploads/2015/03/culture-care-barometer.pdf
- Cancer Rehabilitation Pathways https://www.macmillan.org.uk/assets/macmillan-cancer-rehabilitation-pathways.pdf

Provider Tool

Through the triangulation process six key values were identified:

- Value 1: Involves the patient, is outcome/goal focused and incorporates holistic care
- Value 2: Is accessible and timely
- Value 3: Care is coordinated and there is good communication between the MDT and to the patient
- Value 4: Staff are adequately trained to provide specialist care
- Value 5: Ensures exemplary patient experience
- Value 6: Management and Leadership

In developing the tool, a number of statements relating to each theme were identified. A Likert scale (used to represent people's attitudes to a topic) was introduced for each statement from

never (0 points) to **always (4 points).** This scoring system allowed providers to identify strengths, and areas where they could consider service improvement opportunities.

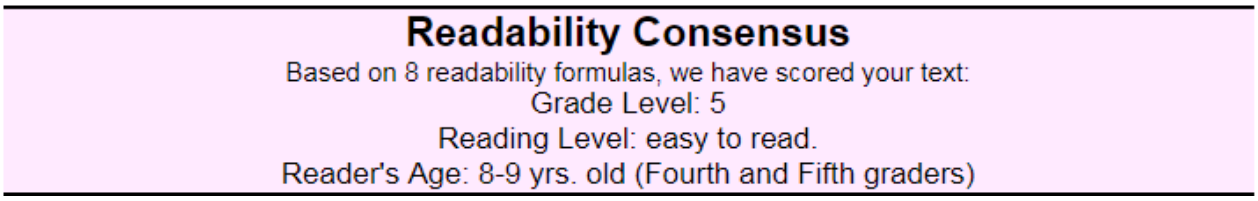
Service user tool

The service user tool was developed to give providers an opportunity to gain constructive real time and personalised feedback for their action planning, and to enable patients and carers to highlight areas that are most important to them

The user version was developed to mirror the values in the provider tool. The tool was 'translated' into plain language by GW who had undertaken training in writing and developing Easy-English and Plain English resources. Content was then checked using an online Free Text Readability Consensus Calculator which tested the content using eight readability formulas including:

- The Flesch Reading Ease formula
- The Flesch-Kincaid Grade Level
- The Fog Scale
- The SMOG Index
- The Coleman-Liau Index
- Automated Readability Index
- Linsear Write Formula

Figure 3: Results of the Readability Consensus Calculator



Liaison with NHS Improvement

There was recognition that aspects of the project fitted well with the Model Hospital project currently being led by NHS Improvement. The Model Hospital is an online digital tool provided by NHS improvement to help trusts identify and realise productivity opportunities. It is improvement-focussed, and allows services to identify and compare themselves to high-performing trusts to build a picture of 'what good looks like'. The NHS Improvement team and TCST kept in regular contact throughout the project. There was recognition that there is symmetry between the projects.

5. Piloting

a) Provider tool

First pilot

Four teams at a large acute hospital in London who provide cancer rehabilitation across a range of services (inpatient, outpatient and hospice) and allied health specialties (dietetics, occupational therapy, physiotherapy) piloted the tool. Feedback was positive and demonstrated that the tool has clinical usability. All teams indicated it was useful to their practice, it was easy to use, and that they would want to implement it as a standard evaluation tool to be used regularly. All teams said that the statements throughout the tool gave them ideas for potential service improvement opportunities that they could implement. A copy of the feedback form used in both pilots can be found in Appendix C. Feedback from both pilots is summarised in Appendix G.

Second pilot

Following feedback from the first pilot, amendments were made to the tool as required and then the tool was put out for a second pilot. All attendees of the consultation event were invited to be part of the pilot. Additionally, other sites known to deliver cancer specific rehabilitation services were invited to participate. A range of diverse cancer rehabilitation teams across 5 sites, with members ranging from junior staff to senior managers piloted the tool:

- Large district general hospital (cancer services): 1x Physiotherapist, 1x Occupational Therapist
- Large acute NHS hospital with tertiary services: 3x Occupational Therapists
- Private cancer care facility: 2x Physiotherapist, 1x Breast Care Nurse
- Acute Trust cancer services:1x Clinical Lead Physiotherapist, 2x Physiotherapist, 2x Occupational Therapist
- NHS Hospice: 1x Physiotherapist, 1x Occupational Therapist, 1x Rehab Assistant

Two services completed a paper version of the tool and three services piloted the tool online, however, some limitations were noted with putting the tool into the online survey tool, ‘Survey Monkey’.

Feedback from the second pilot was positive; services appreciated the opportunity to take time away from delivery to consider their own practice and all services planned to put together an improvement action plan. One service indicated that there was potential for more direction to be given after the tool was completed with regards to how the services could formulate an action plan.

Additional feedback mechanisms

The tool was also socialised at numerous meetings across London. Attendees were asked to consider the tool and how it would be used in practice, as well as how it would be useful for the sector as a whole. The tool was also taken to an Irish Society of Chartered Physiotherapists Study Day in Dublin (where Karen Robb was presenting) and was reviewed by almost 90 physiotherapists as part of a workshop session. Barriers to implementation were identified, as well as potential solutions to these. These are outlined in Table 2.

Table 2 Barriers to implementation and suggested solutions	
Perceived barrier	***Suggested solution***
• Finding time away from practice	Set aside dedicated time each month, utilise team meeting where team will be together
• Funding to allocate to improvement activities	Look for local/third sector grants and opportunities
• Workplace culture not receptive to change/resistance	Educating those who are resistant to the changes Utilising change management strategies
• Not perceived as relevant to service	Educating service on relevance

b) User tool

The initial iteration of the service user tool was deemed too long and the wording too complicated. After review and translation to plain language, the document was sent out to three therapy teams who had worked with TCST to pilot the provider tool. Each team was asked to complete the pilots over a three-week period and asked to randomly select appropriate patients to complete the tool and provide feedback. TCST received 8 completed forms and the T&F group met to discuss the feedback and refine the tool. Only minor amendments were required.

6. Reporting and approvals

- Both tools were approved by the TCST Cancer Rehabilitation Steering Committee on 27th November 2018.
- The tools were presented as part of a work stream update to the Pan London LWBC partnership Board on 11th September 2018, the Cancer Delivery Board on 25th September 2018 and the Cancer Commissioning Board on 9th October 2018. No amendments were advised.
- Two posters were presented at the European Cancer Rehabilitation and Survivorship Conference (ECRS) in September 2018.

7. Discussion

The TCST Service improvement tools for rehabilitation have been developed through extensive stakeholder engagement and evidence building activities. The user voice has been at the heart of this work. The tools outline a clear framework for what good cancer rehabilitation looks like and what service components are needed for proactive, personalised, accessible and coordinated care to be delivered.

The tools were well received by all providers (n=9**)** and users (n=10) who piloted them, as well the sectors they were socialised through. All providers reported they would use the tools regularly and that there were a range of ways in which the tools could be utilised. Therapy teams felt that the tool would allow them to access feedback and identify areas for improvement. Additionally, therapy teams indicated that the tools would help them gain a voice at senior management team meetings, including at Board level, to demonstrate the importance of cancer

rehabilitation services. This in turn would support strategic conversations with commissioners. In addition, they would provide the opportunity to undertake service improvement opportunities, which would benefit patients, staff and organisations as a whole. The service user tool provided an important additional layer of feedback. Throughout consultations and the piloting, service providers expressed a desire to be able to compare their own results against other services (especially similar services). There is recognition that this would require dedicated infrastructure. Services indicated that having the tools accessible online would be useful. They also wanted a reminder email to let them know when to fill in the forms again. There is a need for a designated host for the tools to enable this.

Throughout the project, there have been two clear outcomes that have benefitted service users, providers and commissioners. Firstly, the tools as standalone documents provide a number of benefits: they allow staff to assess their own service including patient feedback and allow services to regularly 'check in' and assess their own practice, as well as consider innovative improvement activities. They can act as a motivator for services to identify and become exemplar models of care.

Secondly, the values within the tool have the potential to be used as a framework for benchmarking services against each other. Therapy teams throughout the project regularly reported this. The tools will need revisions to allow this to occur but a clear framework now exists to build upon.

Benefits for the healthcare system

Benefits for Commissioners

The tools:

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

Benefits for Service Providers

The tools:

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

Benefits for Service Users

The tools:

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

Conclusion

TCST service improvement tools have undergone a rigorous development process with input from key stakeholders across the health system. There has also been consideration of existing resources. The user voice has been at the centre of the project. There is enthusiasm across the system to implement these tools and potential for multifaceted uses. Overall the tools provide multiple benefits to the system.

Recommendations

1. Embed the service improvement tools into clinical practice. This will require endorsement from CCGs, STPs, Alliances and continued support from TCST for implementation.
2. Cancer rehabilitation services to meet with senior managers/local commissioners to speak about their experiences with the tools, and about service improvement opportunities they have identified through the process
3. As a next phase of this work, the tools could be used to allow benchmarking between services. This would require infrastructure that can support this, such as the NHS Improvement Model Hospital.

Next steps

1. TCST will work with Macmillan Cancer Support to launch the tools together with the report on the Macmillan Cancer Support website, alongside a communications plan and evaluation framework (Dec 2018)
2. TCST will refine the tools following a 6-month evaluation period (June 2018)
3. TCST will use findings from this work to inform the TCST Commissioning Guidance for Cancer Rehabilitation due April 2019
4. TCST will continue discussions with Macmillan Cancer Support and partner organisations to support benchmarking activities across services

References

- NHS England Rehabilitation is everyone's business: Principles and expectations for good adult rehabilitationhttps://www.networks.nhs.uk/nhs-networks/clinical-commissioning-community/documents/principles-and-expectations

- The Macmillan Allied Health Competence Framework for Professionals working with people affected by cancerhttps://www.macmillan.org.uk/_images/allied-health-professions-framework_tcm9-314735.pdf

- NHS England Culture of Care Barometer https://www.england.nhs.uk/wp-content/uploads/2015/03/culture-care-barometer.pdf

- Cancer Rehabilitation Pathways https://www.macmillan.org.uk/assets/macmillan-cancer-rehabilitation-pathways.pdf

- NHS England Commissioning Guidance for Rehabilitation, March 2016: https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf

Appendix A – Service Improvement Tool

Cancer Rehabilitation Service Improvement Tool: Service Provider version

This tool was developed by the Transforming Cancer Services Team **(TCST)** for London. The work was fully funded by Macmillan Cancer Support.

November 2018

Acknowledgements

TCST would like to thank the Task and Finish Group for their time and effort:

- Georgina Wiley (project lead) – Macmillan Project Facilitator, Transforming Cancer Services Team for London
- Karen Turner - Oncology Therapy Service Lead & Clinical Specialist Physiotherapist, Royal Free London NHS Foundation Trust & Marie Curie Hospice, Hampstead.
- David Jillings - Trustee, the Pelvic Radiation Disease Association
- Mandy Shewbridge - Macmillan Nurse Programme Manager for Living With and Beyond Cancer South East London Accountable Cancer Network, Guys Hospital
- June Davis - National Cancer Rehabilitation Lead, Macmillan Cancer Support
- Vanessa Brown – Senior Macmillan Project Manager - Living with and beyond Cancer, RM Partners.
- Dr Karen Robb – Macmillan Rehabilitation Clinical lead, Transforming Cancer Services Team for London.

We are also grateful to Ros Campbell from NHS Improvement for her encouragement and support, to all the clinicians and users who have supported this work and to the TCST Cancer Rehabilitation Steering Committee for oversight and guidance.

How to use this tool

1. This tool is intended to be used in a team setting and should be used in conjunction with the TCST service user tool (available here)
    a. It is recommended that you allocate time away from clinical practice or complete in a team meeting
    b. All team members should consider the contents of the tool prior to the meeting including examples of both good and improvable practice.
2. There is also an accompanying service user feedback form. This form correlates directly to the statements in this tool.
    a. It is recommended that this feedback form is given to patients prior to the team completing the form and that feedback is compiled for discussion by the team after completing this tool.
3. It is recognised that clinical environments do not provide extensive amounts of time away from practice. With this in mind the tool has been designed to be completed within 20-30 minutes.
    a. After completing the tool, time should be allocated for a follow up meeting where the results can be discussed and an action plan formulated. Service user feedback can also be discussed at this time
4. This tool is divided into six (6) values. Each value has a number of statements relating to your service.
    a. You are asked to rate each statement from **never (0 points)** to **always (4 points).**
    b. At the end of each section you will be asked to add up your scores, take time to identify areas where you are performing well and areas where you may like to consider service improvement opportunities.
    c. The evidence section is optional but we recommend you include evidence where possible for example: audits, patient feedback, patient satisfaction questionnaires etc.
5. This tool has been designed with the purpose to regularly take the time to check in on your service. It is recommended that this tool is utilised at least every 6 months and that progress is measured, celebrated and recorded.

We would love to hear if you have any questions about the tool, as well as how the tool has been used in your service, any service improvement activities you have undertaken as a result of utilising this tool, and the outcomes of these. Feedback can be provided by completing the service improvement tools evaluation form provided online here, or by downloading the printable version here and sending to the TCST team on england.tcstlondon@nhs.net.

Background

In 2016 the Transforming Cancer Services Team (TCST) undertook a project to better understand the scope of cancer rehabilitation services in London. Recommendations in the final report included need for a suite of resources to support commissioning of cancer rehabilitation services, including a benchmarking/service improvement/audit tool.

A task and finish group was formed and project scope was agreed upon. The T&F group felt the tool should provide opportunity for teams to consider potential service improvement opportunities. The group sought to develop a tool that:

- Was applicable to all cancer rehabilitation services (acute, community etc.)
- Included opportunity for services to consider areas for improvement as well as recognition of good practice
- Included aspects important to both users and services
- Was score-able and able to be revisited

Two consultation events were held, one aimed at users and one at providers. Each event sought to understand the essential aspects of service delivery, what themes should be included in the tool and how it should be utilised. The NHS England 'Principles and Expectations of Good Adult Rehabilitation' was also an essential resource during tool development. Following the consultation event it was agreed that two tools were needed; one for service providers to complete and one for service users. Please see https://www.macmillan.org.uk/assets/cancer-rehabilitation-service-improvement-tool-service-user.pdf for the service user form.

The following key themes were identified as important for cancer rehabilitation services:

- Providing patient centred/outcome focused care
- Accessible and timely service
- Co-ordinated care
- Good communication
- Compassion and understanding in care giving
- Staff providing specialist care
- Adequate resourcing

In addition, providers felt the tools gave opportunity to improve patient care and experience, build evidence base for service development as well as time to focus on team objectives.

Results of this process have been reflected within the service improvement tools. The tools have been piloted in London across a range of services. The final products will be included within a suite of resources in upcoming commissioning guidance and it is hoped that they will also be utilised and embedded into practice across London.

Relevant reading:

- NHS England Rehabilitation is everyone's business: Principles and expectations for good adult rehabilitation https://www.networks.nhs.uk/nhs-networks/clinical-commissioning-community/documents/principles-and-expectations
- The Macmillan Allied Health Competence Framework for Professionals working with people affected by cancer https://www.macmillan.org.uk/_images/allied-health-professions-framework_tcm9-314735.pdf

Section One: Overview of Service

1. Name of your service:

2. Lead contact person and their contact details

3. Location of service (name all boroughs your service provides care for)

4. Provider type *NHS* *Voluntary* *Local Authority* *Other (add details)*

5. Summary of service - *Please select all that apply and list others that you feel may be relevant in the 'other' space*

Community	*Primary care*	*Home*
Secondary care inpatient	*Secondary care outpatient*	*Hospice*
Tertiary/specialist inpatient	*Tertiary/specialist outpatient*	Cancer specific
Other (add details)		
……		

6. How would you describe the purpose of your service? *Please select all that apply and list others that you feel may be relevant in the 'other' space*

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

Section Two: Values

Value 1: Involves the patient, is outcome/goal focused and incorporates holistic care

- Individualised service which involves the patient in both decision making and planning.
- Is outcome/goal focused and considers the patient holistically not just in the context of their cancer diagnosis.
- Incorporates practical support.
- Ensures patients are aware of what is going to happen including what rehabilitation services are available to them
- Includes input from both carers and family members – recognising that cancer does not just affect the person with the diagnosis

This section refers to SMART goals. While there are different versions of the SMART acronym the most common version is Specific, Measurable, Attainable, Relevant and Timely.

	Never (0)	Seldom (1)	Sometimes(2)	Often (3)	Always (4)	Example/Evidence (optional)
Our patients say our service:						
1. Puts patients at the heart of everything we do						
2. We take the time to ask patients what matters to them						
3. Provides individualised care tailored to each patient and their current situation						
4. Considers the patient holistically in consideration of all aspects of their life- including practical, psychological and physical support						
5. Provides care that is pro-active and goal focused (incorporating SMART goals)						
6. Ensures patients are clear of what their rehabilitation will involve including what goals they are working toward/intended outcomes of their care in						
7. Makes time for regular check-in's with the patient to make sure these goals are still relevant and meaningful and adjust as required						

8. Involves the patients support network in both planning and decision making (as appropriate) recognising that cancer affects the whole family						
	Never (0)	**Seldom (1)**	**Sometimes (2)**	**Often (3)**	**Always (4)**	**Example/Evidence (optional)**
9. Advises what relevant rehabilitation services are available to them in their area						
Examples of what we do well						
Examples of Challenges						
Identified opportunities for improvement						

Total score for Value 1	**/36**

Value 2: Is accessible and timely

- Is easily accessible to all (and consistent)
- available at the time in the pathway when needed
- enough time is allocated in appointments
- looks at the whole pathway of care
- allows access to long-term rehabilitation if needed
- Is accessible to all that require it (has made consideration around equitable care: access to interpreters, wheelchair access etc.)

	Never (0)	Seldom(1)	Sometimes(2)	Often (3)	Always(4)	Example/Evidence (optional)
Patients say our service:						
1. There is awareness in the catchment area that the service is available. It is clearly signposted for those who need it						
2. Is accessible at the following points along the patient pathway or signposts to an appropriate service for their needs (e.g. referring back to community and primary care after completion of treatment)						
Before treatment (prehab)						
During treatment						
After treatment						
Palliative care						

3. Ensures service is accessible to all that require it (Health Equity). Consideration is given to how the service is accessed including access to interpreters, access for wheelchairs etc.						
4. Offers treatment at time and place that suits without undue delay*						
5. Allocates enough time for appointments						
6. Ensures that outpatients are generally seen within 10 minutes of their appointment time and inpatients within a day of being referred*						
Examples of good practice						
Examples of Challenges						
Opportunities for improvement						

*please refer to your local criteria and targets

Total score for Value 2	**/36**

Value 3: Care is coordinated and there is good communication between the MDT and to the patient

- Consistent coordinated care with good communication between the whole MDT (including the patient) – including use of a treatment summary
- Good signposting (including knowledge of available services)
- Makes sure the patient is aware of what is happening and will happen including need for cancer rehabilitation and what services are available
- Regular updates provided to the patients GP
- Good communication in and out within a service

	Never (0)	Seldom (1)	Sometimes (2)	Often (3)	Always (4)	Example/Evidence (optional)
Patients would be aware that our service:						
1. Discusses all patients regularly within a local MDT or equivalent meeting						
2. Establishes a lead point of contact for each patient under our care (including contact numbers and/or an out-of-hours number for emergencies as appropriate)						
3. Develops a coordinated treatment plan which includes input from all key relevant professionals						
4. Where a patient is receiving treatment from more than one service, we make sure that the other service is aware of what we are doing, and vice versa						
5. Provides regular updates to the users GP						
Examples of good practice						

Examples of Challenges	
Is there anything you would add to your service?	
Opportunities for improvement	

Total score for Value 3	**/20**

Value 4: Staff are adequately trained to provide specialist care

- Service is provided by trained professionals who are able to provide specialised expert care

This section refers to levels of competency (competent, specialist, highly specialist) as set out by the Macmillan Cancer Support document: Allied Health Professions Competence Framework. The framework includes the range of skills and knowledge required by AHPs working with people affected by cancer. The competence clusters also reflected and referred to throughout all of the values.

For more information and to view this document: https://www.macmillan.org.uk/_images/allied-health-professions-framework_tcm9-314735.pdf

	Never (0)	Seldom(1)	Sometimes(2)	Often (3)	Always(4)	Example/Evidence (optional)
Our service:						
1. Is provided by professionals who have been deemed competent (or above) on their knowledge of cancer and its treatment and are able to explain treatments and options clearly including: • Types of cancer treatments • Tests and results commonly used • Symptom management including long term and late effects and complications						
2. Is provided by professionals who have been deemed to have competent (or above) knowledge of the recovery package and how the components of these relate directly to their practice:						
3. Is provided by professionals who have been deemed competent (or above) on their understanding of the issues patients may experience when completing treatment and transitioning from acute care						

4. Ensures staff have access to further specialist training, education and support							
5. Ensures all care given makes optimal use of available evidence by basing it on best evidence based practice							
6. Identifies areas that require further research and seeks to add to the evidence base							
Examples of good practice							
Examples of Challenges							
Is there anything you would add to your service?							
Opportunities for improvement							

Total score for Value 4	**/28**

Value 5: Ensures exemplary patient experience

- Care given is compassionate, supportive and understanding

	Never (0)	Seldom (1)	Sometimes (2)	Often (3)	Always (4)	Example/Evidence (optional)
Patients say our service:						
1. Is supportive and understanding						
2. Is enabling and empowering						
3. Explains treatments and options clearly						
4. Ensures patients are aware of what is going to happen during and after their rehabilitation including intended outcomes.						
5. Provides opportunity (as appropriate) to meet others who have had the same experience (through Health and Wellbeing events among others)						
6. Seeks opportunity to promote behaviour change						
Examples of good practice						
Examples of Challenges						

Is there anything you would add to your service?	
Opportunities for improvement	

Total score for Value 5	**/ 24**

Value 6: Management and Leadership

	Never (0)	Seldom (1)	Sometimes (2)	Often (3)	Always (4)	Example/Evidence (optional)
We would say our service: :						
1. Is well managed						
2. Is well led						
3. Has a positive culture						
4. Places emphasis on recruiting and retaining the right people to the right jobs						
5. Ensures all staff have yearly appraisals						
6. Places emphasis on 100% completion of mandatory training						
7. Ensures notes are written on the day of patient treatment						
8. Is innovative and seeks to lead service improvement initiatives						
9. Is seen as a priority by our organisation						
10. Is aware of relevant legislations and guidelines that directly link to practice and work within these						
11. Seeks to involve users in service improvement through feedback and co-design						
Examples of good practice						

Examples of Challenges	
Is there anything you would add to your service?	
Opportunities for improvement	

Total score for Value 6	**/44**

Total Scores	
Value 1	
Value 2	
Value 3	
Value 4	
Value 5	
Value 6	
All scores	**/188**
Percentage score	**%**

Summary
Action areas for next 6 months
Next Steps

Review date (six months from now

Appendix B – Service User Feedback Form

Cancer Rehabilitation Service Improvement Tool:

Service User version

This tool was developed by the Transforming Cancer Services Team **(TCST)** for London. The work was fully funded by Macmillan Cancer Support.

November 2018

Acknowledgements

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We are also grateful to Ros Campbell from NHS Improvement for her encouragement and support, to all the clinicians and users who have supported this work and to the TCST Cancer Rehabilitation Steering Committee for oversight and guidance.

How to use this tool

1. This service user tool is intended to be used alongside the service provider version (available here)
2. We recommend this form is given to a selection of patients (to be decided locally) prior to the team completing the service provider tool, and that feedback is compiled for discussion by the team after completing this tool.
3. This tool has been designed with the purpose to regularly take the time to check in on your service. It is recommended that this tool is utilised at least every 6 months and that progress is measured, celebrated and recorded.

We would love to hear if you have any questions about the tool, as well as how the tool has been used in your service, any service improvement activities you have undertaken as a result of utilising this tool, and the outcomes of these. Feedback can be provided by completing the service improvement tools evaluation form provided online here, or by downloading the printable version here and sending to the TCST team on england.tcstlondon@nhs.net.

Background

In 2016 the Transforming Cancer Services Team (TCST) undertook a project to better understand the scope of cancer rehabilitation services in London. Recommendations in the final report included need for a suite of resources to support commissioning of cancer rehabilitation services, including a benchmarking/service improvement/audit tool.

A task and finish group was formed and project scope was agreed upon. The T&F group felt the tool should provide opportunity for teams to consider potential service improvement opportunities. The group sought to develop a tool that:

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- Included opportunity for services to consider areas for improvement as well as recognition of good practice
- Included aspects important to both users and services
- Was score-able and able to be revisited

Two consultation events were held, one aimed at users and one at providers. Each event sought to understand the essential aspects of service delivery, what themes should be included in the tool and how it should be utilised. The NHS England 'Principles and Expectations of Good Adult Rehabilitation' was also an essential resource during tool development. Following the consultation event it was agreed that two tools were needed; one for service providers to complete and one for service users. Please see https://www.macmillan.org.uk/assets/cancer-rehabilitation-service-improvement-tool-service-provider.pdf for the service provider form.

The following key themes were identified as important for cancer rehabilitation services:

- Providing patient centred/outcome focused care
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- Co-ordinated care
- Good communication
- Compassion and understanding in care giving
- Staff providing specialist care
- Adequate resourcing

In addition providers felt the tools gave opportunity to improve patient care and experience, build evidence base for service development as well as time to focus on team objectives.

Results of this process have been reflected within the service improvement tools. The tools have been piloted in London across a range of services. The final products will be included within a suite of resources in upcoming commissioning guidance and it is hoped that they will also be utilised and embedded into practice across London.

Relevant reading:

- NHS England Rehabilitation is everyone's business: Principles and expectations for good adult rehabilitation https://www.networks.nhs.uk/nhs-networks/clinical-commissioning-community/documents/principles-and-expectations
- The Macmillan Allied Health Competence Framework for Professionals working with people affected by cancer https://www.macmillan.org.uk/_images/allied-health-professions-framework_tcm9-314735.pdf

Service User Feedback Form

We would be grateful for your feedback to help us to evaluate our service. Please tick the box that you feel best applies to the service you have received. If you do not know, or cannot answer the questions, then please tick 'unsure'. There is space for additional comments at the end of the document.

It is expected that this will take no longer than 5-10 minutes to fill in. If you need any help to fill in the form please let a member of staff know. Please return the form to a member of staff after use.

Please note that if you do not wish to participate, your care will not be affected in any way. All information you provide will be treated confidentially.

	Never	Seldom	Sometimes	Often	Always	Unsure
I feel this service:						
1. Puts patients at the heart of everything they do						
2. Provides care that works for me and can change when my needs change						
3. Considers me as a whole person, including my mental health, physical health, home life and work life						
4. Takes the time to ask me what matters to me						
5. Explains my rehabilitation options clearly						
6. Makes sure I know what is going to happen to me while receiving rehabilitation						
7. Provides me with goals that help me to live my life the way I want to						
8. Makes time for regular check-ins to make sure my treatment is still what I want and need						
9. Involves the people around me in making decisions, if I want them to be involved, knowing that my health affects not only me						
10. Knows what other services are available to me in my area						
11. Was easy for me to find out about *(circle as appropriate)*	YES	NO				
12. Is there when I need it, or can send me to another service that can help me						
13. Is easy to access (this could include wheelchair access, interpreters for those who don't speak English etc.)						

	Never	Seldom	Sometimes	Often	Always	Unsure
I feel this service:						
14. Is easy to get an appointment at *(outpatient only)*						
15. Sees me within 10 minutes of my appointment time *(outpatient only)*						
16. Gives me enough time in our session(s)						
17. Gives me opportunity to feedback						
18. Is supportive and understanding						
19. Makes me feel empowered						
20. Gives me opportunities to meet others who have had the same experience (e.g. at Health and Wellbeing events)						
21. Discusses my needs and care enough with other professionals						
22. Provides me with a contact person (including contact numbers and/or an out-of-hours number for emergencies) *(circle as appropriate)*	YES	NO				
23. Develops a rehabilitation plan with input from me and all professionals who are involved in my care						
24. Makes sure other services I am receiving treatment from know the care I am receiving						
25. Provides enough updates to my GP						
26. Makes me feel the staff are experts in what they are doing						
Additional Comments						

Thank you for your time

Appendix C – Pilot Feedback Form

Documentation Review Checklist				
Document Title:		**Review Date:**		
Reviewer(s):				
Section	**Item**	**Y**	**N**	**Comments/Changes**
Purpose and Scope	The purpose of the document is clear.	☐	☐	
	All known audiences/users are described thoroughly and accurately.	☐	☐	
	The scope of the document is accurate	☐	☐	
Content	The document flow and structure logical for the audience to follow.	☐	☐	
	Spelling and grammar check are complete.	☐	☐	
	The document text is concise and clear.	☐	☐	
	Are there any additional statements you would include in the tool?	☐	☐	
Online Survey	The survey was easy to use			

	Any technological issues?			
	Did it work as an online tool? If not what needed to change?			
Action Planning	What activities have you committed to over the next 3-6 months?			
	Would you use the tool regularly?			
Service User Feedback	Was this useful to your team?			
	Did the feedback differ to what you were expecting? How or how not?			
What do you see as the purpose of a benchmarking tool for cancer rehabilitation services?				
What do you see as the purpose of a benchmarking tool for commissioners?				
How do you see a benchmarking tool like this one being used in your own service?				
Other comments				

Appendix D – Example of tool being used

Section Two – the Tool

Value 1: Involves the patient, is outcome/goal focused and incorporates holistic care

- Individualised service which involves the patient in both decision making and planning.
- Is outcome/goal focused and considers the patient holistically not just in the context of their cancer diagnosis.
- Incorporates practical support.
- Ensures patients are aware of what is going to happen including what rehabilitation services are available to them
- Includes input from both carers and family members – recognising that cancer does not just affect the person with the diagnosis

This section refers to SMART goals. While there are different versions of the SMART acronym the most common version is Specific, Measurable, Attainable, Relevant and Timely

	Never (0)	Seldom (1)	Sometimes(2)	Often (3)	Always (4)	Example/Evidence
Our patients say our service:						
1. Puts patients at the heart of everything we do					✓	Patient records.
2. We take the time to ask patients what matters to them					✓	Recorded on annotations.
3. Provides individualised care tailored to each patient and their current situation					✓	" " "
4. Considers the patient holistically in consideration of all aspects of their life- including practical, psychological and physical support					✓	" " "
5. Provides care that is pro-active and goal focused (incorporating SMART goals)		✓				No evidence.
6. Ensures patients are clear of what their rehabilitation will involve including what goals they are working toward/intended outcomes of their care in				✓		But verbally rather than written down
7. Makes time for regular check-in's with the patient to make sure these goals are still relevant and meaningful and adjust as required					✓	But informally rather than documented.
8. Involves the patients support network in both planning and decision making (as appropriate) recognising that cancer affects the whole family					✓	Recorded on annotations.

	Never (0)	Seldom (1)	Sometimes (2)	Often (3)	Always (4)	Example/Evidence
9. Advises what relevant rehabilitation services are available to them in their area					✓	Recorded on annotations.
Examples of what we do well	Thorough assessment & record of patient's performance on annotation. Excellent liaison with staff, patient & relatives. Good follow through with rehab. programme.					
Examples of Challenges	Lack of written evidence of SMART goals. Lack of formal outcome measures with treatment goals.					
Identified opportunities for improvement	- OTs to use Barthel Scale as initial assessment & follow up outcome measure. - Use laminated goals poster on ward with physios so goals are visible. - Investigate & introduce GAS & score it with patients. - Ultimately, use as an educational tool on wards for therapy service re. role of therapists.					

Total score for Value 1	25 /36

Appendix E - Service User event summary. What do patients want from a cancer rehabilitation service?

Value	Looks like	Evidence from event
Involves the patient - is outcome/goal focused and incorporates holistic care	Individualised service which involves the patient in both decision making and planning.	• I have awareness of my particular concerns/lifestyle/circumstances • Therapists factor in my abilities and do not assume that I'm like everyone else • Service is tailor made to meet individual and family needs • The provider understands my history and my priorities • Care is personal, of value and relevant to me • Rehabilitation feels doable, I understand what is going to happen, I can cope, and it feels realistic • Care is holistic and compliments my medical care • I want a holistic rehab plan which includes complementary therapies such as acupuncture, lymphatic drainage, reflexology, reiki etc. • I know what is going on and am regularly informed • Rehab should be offered and planned with me post treatment • Support is tailored to each individual patient as per our needs • Care is personalised – what is important to me is recognised • Treatment is specific to my needs • An individual plan based on 1-2-1 with dietician/physio consultation • Having someone who knows about me and how I feel • Staff are familiar with problems like mine • Rehab is based around my needs • I am listened to • I am treated as a valued guest • Staff have enough time to talk and get to know me • I am given an individual plan for diet and physical activity • Services are tailored as much as possible to individuals, bespoke • Rehab takes into account the cancer site and treatments. Not all cancers have the same need for rehab • Staff know my needs and aspirations • I have an integrated care plan – individualised to keep me as healthy as possible • There are lymphoedema services • A non-one size fits all approach • Holistic

		• I am involved in designing service – patient voice • Rehab designed for all stages – primary and secondary • More focus on my speech quality • Service relates to me, what I need might not be what someone else needs and vice versa
	Is outcome/goal focused and considers the patient holistically not just in the context of their cancer diagnosis. Incorporates practical support.	• My care achieves a 'good end' or back to normal/as were (whatever that is) • A plan for physical activity by increasing the amount of exercise over a gradual period • Identifying those at risk of lymphoedema • Early intervention • Proactive referrals to dietitian and losing weight • Resolves challenge/problem • Leaves me with improved quality of life • Rehabilitation that also tackles effectively reducing recurrence risks • Matching your needs to the services which are available – a service professional knowing you is really important • When you see your doctors they have a conversation about what is going to happen to you and what will happen but they don't have a conversation about how you will cope with that and what services are available to you and how to access them – none of the services join up or seem to communicate with each other • We don't just want to survive
	Makes sure the patient is aware of what is happening and will happen, including the need for cancer rehabilitation and what services are available	• It is very important that information is available to access rehab services • Rehabilitation must be there for all, accessible and people following treatment for cancer knows this available to them • Being told what rehab services are available • There was no rehab available for my first 2 cancers • What on offer and how to obtain • Knowing what services are out there • When you see your doctors they have a conversation about what is going to happen to you and what will happen but they don't have a conversation about how you will cope with that and what services are available to you and how to access them – none of the services join up or seem to communicate with each other
Is accessible and timely	Is easily accessible to all (and consistent), available at the time in the pathway when needed and	• Rehab services need to be accessible to all patients • Equitable and fair services throughout • Consistent

	enough time is allocated in appointments, looks at the whole pathway of care and allows access to long-term rehabilitation if needed. It is easy for people to gain access (and there is self-referral available). Services are focused on providing equity of care not just equality	• 5-star accessible and consistent levels of services across London • Sufficient treatment to help patient lead best possible life • Long term • More flexible and tailored approach to suit individuals conditions and needs • Treatment at time and place that suits me • Group practices – when you get a consultation you will get a different GP every time and you have 5 minutes to see them. They will be aware of you at a high level through reading the highlights of your notes but won't know you and your history and what you need • When you're receiving cancer treatment and you are the centre of attention you're not thinking ahead to the day when you're on your own and needing to access services and how you go about this • It's about timing – once you have completed chemotherapy or radiotherapy the last thing that you want is to launch into rehabilitation but when you are ready for it the channels to access it may no longer be available • There is a need to consolidate services but they also need to be accessible • The after effects of cancer can last for a long time – it's not just 6 months to a year after treatment, I know people who may not need assistance straight away but 2 years later do
Care is coordinated and there is good communication between the MDT and to the patient	Consistent coordinated care with good communication between the whole MDT (including the patient).	• Consistency of professional • Continual follow up support • Telephone support between appointments • Being able to reach the team through online methods – email for example • Annual health checks • Follow up and support not only at time but on-going (in my case 10 years) • Provided for long enough • Dental support • GP can be a barrier to access services particularly if you don't know GP well • A long term support system • Continuity, consistency and knowledge-ability at primary care level • Not acting in isolation • A wide range of therapies including counselling • Referral to on-going support, e.g. Specialist survivor groups for on-going support after treatment • When you see your doctors they have a conversation about what is going to happen to you and what will happen but they don't have a conversation about how you will cope with that and what services are available to you and

		how to access them – none of the services join up or seem to communicate with each other • I needed to coordinate my own care – I needed to know what to be asking for
	Harmonisation of various care management services: a 'One Stop Shop' – the ability to visit and see all health professionals required at one time	• Integrated one stop shop – I don't drive! • An integrated one stop service – I don't drive and need to take transport • There would always be long waiting times to access these services, I don't know if there could be opportunity for these services to be available at the clinic and you could see them while waiting for your doctor • A dedicated team offering a range of services with regular communication • Harmonisation of various care management services • Access to each type of service is a joined up process and well-coordinated
	Good signposting (including knowledge of available services)	• All hospitals/GPs/health centres distributing info and raising awareness of what is available • Knows what other services are available which might help • Help and support for people with health conditions
	Makes sure the patient is aware of what is happening and will happen including the need for cancer rehabilitation and what services are available	• More detailed information re: cancer, outcome
	Regular updates provided to the patients' GP	• I have 16 consultants, my GP can't join in all up, need someone to coordinate • More support for GPs in managing cancer patients • In touch with my GP • A number/person to call outside scheduled appointments • GP who specialises in cancer • At primary care level clinicians need to know about me and the services • My GP is aware of my needs and where to go to resolve them • Beneficial treatments i.e. complementary therapies • not recognised/valued by GP • Need to see GP as a central point to the service – they need to know who to refer you to
Staff are adequately trained	Service is provided by trained professionals who are able to provide specialised expert care	• Appropriate medication to correspond with the diet and the reasoning behind • The optimum way to build up strength but at the same time eat healthily • Identifying those at risk of lymphoedema

to provide specialist care		• Appropriate advice on food to eat immediately after surgery and ongoing • Access to a therapist who specialises in cancer • Must be familiar with my condition and problems • I want a dietitian who knows about 'work arounds' such as high powered blenders. The same applies to speech and swallowing therapists
Care given is compassionate, supportive and understanding	Care given is compassionate, supportive and understanding	• Polite and professionals • Always ready to help • That the people involved are well informed, supportive and listen
Incorporates exposure to others who have had the same experience	Health and wellbeing events	• Having a support group and being part of it • Being involved with other people • Having participants in the service who have had a similar treatment • Opportunities to share experiences with others. Survivors – share tips e.g. Healthy eating • Being put in touch with other patients who are further along the line with treatment • Links with patient support groups • Workshops which explain why some things work and others don't. and the reasoning behind the advice e.g. what is actually happening in the body • Involving patients in teaching/wellbeing events
Is available to families – recognising that a cancer diagnosis not only affects the person with cancer		• Services should also be available to patient's family etc. It's not just about me as an individual it's about my whole family who have been affected by the experience
Service Limitations		• Not enough staff to meet need • I would rather go to my GP practice and talk to a nurse that knows about cancer services available than my GP who doesn't know what is going on • There aren't enough resources given to services to support the care they are giving • Service given not helpful/didn't see any improvements • Postcode lottery

Appendix F: Service Provider event information collected summary

Key elements of a cancer rehabilitation service	
Theme	Times mentioned
Operational	
Resources (information/equipment/staffing/funding)	5
Excellent facilities	4
Care coordination	
Easy access points at all points along patient cancer journey/smooth transition of care/ Flexible	9
Integrated between acute and community	5
MDT	5
Communication	1
Evidence based	1
Patient Experience	
Accessible	6
Symptom Control/management	5
Goal orientated	4
Patient centred	4
Meaningful to patient/individualised	3
Holistic	3
Early intervention	2
Self-management	2
Proactive	2
Delivery options	2
Element of support network	1
Timely	1
Enablement	1
Staffing	
Specialists providing care/ Clinical expertise	5
Right skill mix	1
high quality care	1

Perception of what is important to service users	
Theme	*Times mentioned*
Operational	
Accessible - timely, close to home, convenient	16
Flexible/able to stop start/ options	6
Not time limited / available when needed	4
Good equipment/inspiring environment	4
Care coordination	
Good communication – between MDT and with patient ‘system level communication’	8
Integrated – clear pathways – coordinated and seamless transfer of care – signposting	6
Patient Experience	
Feel of the service: Supportive/Being listened to/Honesty from staff	4
Patient owned/patient centred	3

Quality care / enough time with patient/ Enough time for appointments/enough appointments	3
Goal/solution focused	2
Addresses QoL/Holistic	2
No wait lists	1
Options	1
Ability to self-refer	1
Staffing	
Clinical expertise/specialised staff	5
Right time, right place, right person	1

Attributes of a gold star service	
Theme	*Times mentioned*
Operational	
Available at all points of the patient pathway (including prehab)	9
Accessible: to all patients groups – language/physical needs thought of, Minimal waiting lists, access outside primary care, easy access to clinicians	6
Flexible: including 7 day extended service Patients decide their own appointment times	5
Five star equipment available	4
Well-funded services	3
Real time data to measure service/value based outcomes collected	2
Clear service pathways/ accessible through single point of access	2
Suitable environment for AHP needs	2
Proactive, Reactive, rapid	1
Dedicated cancer nurse in primary care	1
Care coordination	
Coordination between services (+ smooth transition between acute and community teams)/involves whole MDT team	15
Holistic/Parity of esteem/Psychological input alongside physical rehab	3
Integrated care	3
Linked to social prescribing	1
Spans health and social care	1
Early intervention from AHPs	1
Patient Experience	
Enabling/empowering and educational	3
Good patient experience:	2
Practical – provides tools to live life and manage symptoms	1
Person centred	1
Transparency	**1**
Supportive, friendly and understanding	1
Responsive to need	1
Good communication	1
Going above and beyond	1
Staffing	

Specialists giving care	5
Increase AHPs working with CNS	1
AHPs in outpatient settings	1
Continuing to upskill staff	1

Barriers to care	
Theme	Times mentioned
Operational	
Lack of resources: equipment/space/staff/funding/ outpatient therapy services	11
Lack of equity in provision in different boroughs/postcode lottery	5
Long waiting lists	4
Organisations work in silos	2
Bureaucracy/priorities	2
Lack of embedded rehab model across cancer care/Rigidity in how patients can access services	2
- Confusion in messaging: Lots of different information – not consistent	2
Tertiary/spec service managers believing rehab should only be provided by primary care	1
Lack of referrals for HPs	1
Not providing proactive rehab in acute/inpatient settings	1
Lack of voice of oncology therapies to senior management	1
Different computer systems	1
Time	1
Transport to get rehab or to continue with rehab	1
Lack of chronic condition rehab space	1
Timing to source info on ongoing referrals	1
Care Coordination	
Poor awareness of services available and what these services do - Patients - Staff	4
Coordination of services between sectors/Lack of clarity in who provides what service/who is responsible for what care	3
No seamless at transition points/continuity of care	2
No link back into hospital team	1
Lack of willingness of Primary Care to engage	1
Gate-keeping of services/fear of the unknown	1
Inpatient acute trust prioritising discharge related issues over rehab input	1
Knowledge of standard rehab teams referring in	1
Access to services outside hospital setting	1
Patient Experience	

Not necessarily person centred or responsive/Not viewing person as holistic	2
Long term outcomes not acknowledged	1
Lack of time to use teachable moments in acute sector	1
Staffing	
Reduced skill professional numbers	4
Education of staff	1
Lack of time to engage with HPs	1
Lack of AHPs in inpatient settings providing rehab	1

Session Two

Purpose of a benchmarking tool
• Educating others
• Common standards
• Advocate what is needed/shows gaps
• Quality of care
• Reflection time
• Seeing the service as a whole
• See what others are doing
• Guidance to build/start service
• Commissioning services – speaking their language

What are the benefits of a tool and how would you use it?
• Connecting up services
• Evidence to back up service development
• Internal evaluation and re-evaluation
• Improving patient care
• Help to provide outcomes
• Comparison of services
• Objectives within team – focus on team objectives
• Drives innovation and new ways of doing things
• Share learnings
• Expansion of team – voice at top table
• Builds the evidence base

Barriers of implementing the tool
• Part of a big picture
• Time
• Ensuring sent to the right person
• Other priorities
• Trust – different interests/implications of results
• Right person completing it
• Threatening title ‘benchmarking’
• Independent workers
• Interface – dashboard, online, print, display data
• Drop down menus
• Accessibility

• Like a cancer peer review

Additional information that should be collected
• Ability to search key words
• Includes an action plan
• Name of service
• WTE of different staff – drop down
• How service fits in to the wider landscape (benchmarking against similar peers)
• Includes a patient satisfaction survey
• Includes a referral form

Appendix G: Feedback from pilots – summary

Table 1 Feedback from pilots	
Feedback given	***Change made / suggestion for change***
Ensure target audience is clear	Edit to introduction to ensure this was clear
The tool took around 20-30 minutes to fill in – teams should be directed to fill in the tool and then arrange another 30 minute timeslot to go through the service user feedback as well as develop an action plan	Noted and agreed on – instructions for use now reflect this (including how the service user feedback form should be used)
Insertion of a N/A column	Suggestion noted and decision held over to see what feedback was received during the second pilot. This was not mentioned in the second pilot
Ensure that the statements are relevant to all services – inpatient team felt that the statements were more geared towards outpatient or community care	Statements revised and re-tested in second pilot with success
If the tool is online ensuring that the team can access a copy of their results + the list of statements as these were important for action plan/goal setting	Noted for future developments
Took longer than the suggested timeframe to complete	Suggested that it takes 20 minutes to complete without comments – take longer if want to add examples in
More direction needed around how to develop an action plan	This was only from one services – everyone else was able to do this through self-direction
Wording in the perspective of the patient means that it misses out some of the aspects of the service	Suggestion made to have both aspects: does your service do this and would your patients say/know you do this?
Minor formatting feedback	Actioned and addressed
Ensure target audience is clear	Edit to introduction to ensure this was clear
The tool took around 20-30 minutes to fill in – teams should be directed to fill in the tool and then arrange another 30 minute timeslot to go through the service user feedback as well as develop an action plan	Noted and agreed on – instructions for use now reflect this (including how the service user feedback form should be used)
Insertion of a N/A column	Suggestion noted and decision held over to see what feedback was received during the second pilot
Add in additional question – is there anything you would add to your service?	Added
Add statement on confidentiality to the final tool around information being collected	Added
Some statements difficult to answer as answering from service user perspective	Taken into consideration