

# What does good cancer rehabilitation look like? Shining light on what matters to those with lived experience

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**Background**  
The Transforming Cancer Services Team for London (TCST) undertook a project to develop a benchmarking tool that could be used by cancer rehabilitation services to examine practice. This project is part of comprehensive guidance currently being developed around cancer rehabilitation due for release in Spring 2019.

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

**Methodology**  
A consultation event was held for users and carers. The event was facilitated by clinicians and TCST. Attendees were asked:  
 • What matters most to you 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?  
 Attendees wrote answers on post-it notes. Notes were arranged into themes. A facilitated discussion was also recorded on a dictaphone. Information from the event was thematically analysed and cross referenced with the 2015 NHS England document *Principles and Expectations of Good Rehabilitation*. A professional artist was engaged to take visual minutes. A selection of attendees were interviewed on camera.

*"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." - Attendee at event*

**Results**  
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. The majority (n=16) were aged over 50, there were more females than males. All attendees had accessed a number of cancer rehabilitation services:

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

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**Key themes**

- 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 service users are aware of what is going to happen including what services are available to them.
- Services which are accessible and timely**
  - Is easily accessible to all (and consistent), available at the time in the pathway when needed and enough time is allocated in appointments, looks at the whole pathway of care and allows access to long-term rehabilitation if needed.
  - Good signposting (including knowledge of available services).
- 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 patients' GP.
  - Makes sure the patient is aware of what is happening and will happen including 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.
- Care given is compassionate, supportive and understanding**
  - Staff take the time to provide care that is not only professional. Care given is always compassionate, supportive and understanding.
- Staff are adequately trained to provide specialist care**
  - Service is provided by trained professionals who are able to provide specialised expert care.
- Incorporates exposure to others who have had the same 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.
- Is 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.
- Enough resources are given to allow the sustainability of cancer services**
  - There is recognition of the importance of cancer rehabilitation services and the nature of the service they provide. Enough funding is provided to allow for adequate staffing or service provision.

**Conclusion**  
Findings aligns to the previous NHS England work. The patient voice has clarified key themes for inclusion in the tool. This project has wider implications for service improvement with learnings relevant across all cancer services. The mural and videos produced will be used to socialise the impact of cancer rehabilitation on users. Once the guidance is published, the tool will be displayed on Macmillan's website alongside other cancer rehab resources. Full testing and evaluation of its use will be undertaken as part of the implementation phase of the guidance.

