Co-design of new post-covid oncology rehabilitation services offers a model for the future

During the covid-19 pandemic the therapies department at the Royal Marsden NHS Foundation Trust, a tertiary cancer hospital in London, had to change the way it delivered cancer prehabilitation and rehabilitation services and move to remote methods. Justin Roe, Grainne Brady, and colleagues, and patient partner Dianne Mowbray-Pape, describe how the department adopted an experience based co-design approach to deliver a new model of service provision which includes telemedicine as well as face-to-face appointments and how their approach is influencing new digital developments in the trust.

Justin Roe, Grainne Brady, Lisa Emery, Susanna Walker, Ione de Brito Ashurst, Dianne Mowbray-Pape

Justin Roe and Grainne Brady, on behalf of the therapies experience based co-design team

The therapies team at the Royal Marsden Hospital comprises a range of allied health professionals including dietitians, occupational therapists, physiotherapists, lymphoedema therapists, and speech and language therapists. The rehabilitation team has a key role in supporting and rehabilitating people affected by all types of cancer. The team provides input before treatment, including prehabilitation where we seek to increase patients’ functional capacity, for example through nutritional optimisation and strength training, and to plan for ongoing support during treatment and beyond. Before the pandemic, our services were delivered almost exclusively face-to-face, but the need to move rapidly to telemedicine prompted us to adopt and evaluate telemedicine services which we codeveloped with staff and patient partners.

Staff and patients who had been involved in video and teleconsultations were invited to take part in an online interview regarding their experience of remote care services between March and July 2020. Patients who were not comfortable participating in online meetings were invited to contribute a written narrative. Twelve staff members and 11 patients took part in the project. No written narratives were received.

The patient participants had engaged in a total of 80 telemedicine consultations before being interviewed, with a median number of telemedicine consults of seven per patient. This included experience of both telephone and video consultations. Patients were recruited across tumour groups including head, neck, and thyroid; breast; gastrointestinal; and haematology. The range of telemedicine interventions included prehabilitation, reviews during cancer therapy, and post-treatment rehabilitation across speech and language therapy, dietetics, physiotherapy, and lymphoedema services. Staff members included in this project included management and admin staff who set up the virtual appointments and clinicians who delivered the interventions.

Using experience based co-design methodology we were able to obtain an in-depth understanding of patient and staff members’ views and concerns regarding the use of telemedicine. Positive aspects included reduced financial and time burden on patients and increased flexibility for staff and patients. Key concerns included digital exclusion, safety, communication, and patient choice. Patients and staff members worked together to ensure that the positive aspects of telemedicine were maintained, including increased access to services for patients who did not wish to attend and the provision of face-to-face appointments when clinically indicated or requested by patients.

Lisa Emery, chief information officer

As the director with responsibility for delivery of digital services at the trust, I was asked to join the experience based co-design project group at an early stage. This has proved invaluable in terms of obtaining a deeper understanding of the way in which the trust needs to adapt and tailor its digital plans. While the pandemic led us to move a number of our services to a remote basis it has also raised challenges and concerns regarding equality of access. Talking about the benefits and challenges raised by staff and patients in detail in the group meetings has highlighted the need to tackle digital inclusion, patient choice, and communication about the range of services available. The trust is looking at options so that patients can express their communication preferences (by email, text, or letter) and support patients to have increased access to remote consultations. Options currently being explored include the use of peer and volunteer support for IT skills in the form of a digital helpdesk. In terms of the impact this has had on the digital agenda in the trust, we are about to embark on the delivery of a new digital health record system. The new system will connect elements of our existing healthcare systems into one integrated platform, connect our research teams with rich clinical data, and connect our staff and patients through a new patient portal. We will ensure that direct patient involvement helps to shape its design and delivery. We will be establishing a patient and public engagement group, led by our chief nurse as a key delivery workstream of the digital health record programme. My engagement with the
project has served to further strengthen my view that co-design of our digital services is critical.

**Susanna Walker, consultant anaesthetist**

While the pandemic has been a catastrophe on many levels, in the world of prehabilitation and rehabilitation we have seen a silver lining. Before being forced rapidly to embrace telemedicine in March 2020, we frequently discussed restrictions in our capacity because of a lack of space. We also recognised that for patients who travel significant distances to reach us, and may have a very onerous burden of medical appointments with variable treatment regimens, additional trips to the hospital for an exercise appointment or prehabilitation advice, for example, would often be a low priority. Our perception when we first switched to virtual appointments was that this opened up the opportunity of accessing this area of healthcare to a larger cohort of patients who were able to access the care from their home a long distance away, or even while on holiday. There is no doubt that in the long term a hybrid solution offering all modes of treatment to account for all preferences will be the most likely solution. Having a robust process to assess that, and a strong patient voice to guide us towards that optimum, has benefitted the Royal Marsden Hospital patient and staff population to help guide our future digital health record processes.

**Ione de Brito Ashurst, head of therapies and rehabilitation**

Participating in this project reinforced the fact that good service design begins with understanding people’s lived experiences. The richness of experience based co-design data cannot be acquired using the typical methods of gathering NHS feedback, such as surveys or comment boxes. It was inspiring to see patients’ appreciation of being part of this co-design project and reinforced the view that this methodology is invaluable. As healthcare professionals we often forget that patients are individuals with valuable expertise that can contribute significantly to making all aspects of the service better for everyone. For example, one of our patient partners had a background in management consultancy and consumer relations. She used her unique expertise to drive ideas to tackle digital exclusion, including the engagement of charities. She was also influential in the development of a standard operating procedure for telemedicine consultations for staff, but also one for patients. Equally important were the views and contributions from clinical staff. Staff were able to raise concerns, discuss their views, and share suggestions for a better service.

**Dianne Mowbray-Pape, patient partner**

Following transoral robotic surgery and radiotherapy to treat a 55 mm tumour at the base of my tongue, I needed extensive support from rehabilitation services (particularly speech and language) at the Royal Marsden early in 2020. Because of the pandemic, the vast majority of this had to be done by telephone or video link. Without the availability of telemedicine services, I would have been unable to access this support, as government guidelines on social distancing meant I was confined to my home. The need to develop telemedicine also worked to my advantage, as I have a round trip of just under 600 miles to get to the Marsden.

I was later approached and asked if I would be willing to work collaboratively with staff in a co-designed project, to share my experience of using telemedicine in rehabilitation in order to improve future services. I initially thought it would be staff leading the changes and seeking patient opinions about their ideas, but I found that I was not just a source of information. The project was a true partnership, with patients often leading suggestions for improvement and staff working with us to make them possible. I have enjoyed being part of the project and it gives me a sense of satisfaction to think that, through the co-design group, I may have been able to make a contribution to helping future patients. An unexpected bonus has been that after watching myself back on video and talking in online meetings I have overcome many of my anxieties about how clearly I can be understood following my surgery, as my speech is much better than I imagined it was.

Going forward, I feel that there should be the option for some remote consultations to save travel time. The development of the hybrid approach by the therapies department is ideal, where patients can still access to face-to-face appointments when required or preferred by the patient.

Learning points:

- The collective voice of patient partners and those who deliver clinical services are our greatest resource in improving care provision
- For staff who do not see patients face-to-face but are involved in service delivery, experience based co-design provides a stronger sense of meaning in their work
- Employing co-design and co-production methodology can impact more widely both for those participating in projects and organisational culture

**Future directions**

Using experience based co-design is now a core component of how we design and deliver services within the therapies department at Royal Marsden Hospital. Through the involvement of a broader stakeholder group, the methodology is being adopted more widely in our organisation. Patient partners are well placed to influence and guide service design and delivery alongside clinical and non-clinical staff within organisations.

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