



**Findings from qualitative research with
patients and carers**

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1 Background

The NHS has an ambitious vision to transform rehabilitation services in the East Midlands and to establish a world-class centre of excellence for rehabilitation in the region. As part of developing the business case for this, [*Transforming Rehabilitation Services*](#) was produced in April 2019 - a paper outlining the plans for transforming rehabilitation services and seeking the views of patients and their families to shape the proposals for the new services.

Patients, carers and other people with an interest in rehabilitation services from across the region have been encouraged to have their say on this issue over a two month period of engagement.

As part of the engagement process, an independent research agency, The Campaign Company (TCC), was commissioned to carry out focus groups and depth interviews with patients across the East Midlands who are currently undergoing rehabilitation or who have recently used rehabilitation services following neurological, musculoskeletal or major trauma.

This report sets out the findings from this qualitative research.

2 Our approach

The overarching aim of the research was to obtain qualitative insight, through focus groups, on patients' experiences of rehabilitation services in the region and their views on the proposals for change.

Focus groups were conducted in NHS or community venues with key patient groups in the following areas:

- **Linden Lodge, Nottingham** – a specialist Neurological Rehabilitation Unit at Nottingham City Hospital which caters for a wide range of neurological conditions for patients across East Midlands (10 participants – 8 patients and 2 carers)
- **East Midlands Major Trauma Centre, Nottingham** – established at Queen's Medical Centre, this Major Trauma Centre is for patients who have multiple injuries that could result in death or a serious disability such as severe head injuries, gunshot wounds or injuries from road accidents (8 participants – 4 patients at focus group and 4 telephone interviews with patients)
- **Headway Derby** – a community-based charity, working closely with the local NHS and Derby City Council, to provide a range of support and development services for brain injured people, their families and carers in Derbyshire. (8 participants – 5 patients and 3 carers/support workers)

A discussion guide was developed for the groups to specifically elicit the following insight:

- Experiences of current rehabilitation services
- What elements of rehabilitation services are most valued and what could be improved
- Views on the proposed changes as outlined in the *Transforming Rehabilitation Services* paper
- The potential impact of these changes from a patient perspective and ways of addressing these

Since it could not be assumed that participants had read the *Transforming Rehabilitation Services* paper, each session also included a contextual presentation of the proposed plans for a National Rehabilitation Centre, as outlined in the paper. This allowed participants to have an informed discussion about the proposals.

It should be noted that qualitative research such as this captures perceptions and attitudes rather than quantifiable data. The aim of this is to accurately capture and assess the range of points put forward rather than to quantify the number of times specific themes or comments were mentioned. Larger amounts of data are needed to analyse information quantitatively and to ensure these are representative of the population.

Relevant NHS commissioners and providers carried out the recruitment for these groups. Their help in enabling these groups is appreciated and we are extremely grateful for the active participation of all patients and carers who took the time to share their views to inform this research.

3 Findings from patient and carer insight

This section of the report provides an overview of the findings from the three focus groups and supplementary telephone interviews. Any differences by type of service or patient groups is noted where relevant.

3.1 Experiences of rehabilitation services

“The staff here are wonderful – I wouldn’t have been able to get through this without them”

“I’m just so grateful – everything I’ve needed I’ve received. Ok – so there are some things that could have been better like the food and communications sometimes but I can’t complain”

“Being so close to home was important for me because it meant my Mum and Dad could see me every day

All participants were current or recent long-term users of rehabilitation services so were able to speak knowledgeably about their experiences at their current facility and other places in the East Midlands (eg Leicester Royal Infirmary and Royal Derby Hospital) where they had received care.

All participants really valued the services that they had received during their rehabilitation. The friendly and attentive staff were mentioned most often as being the most important element of care that they valued. Also important to some was location and convenience particularly for their visiting families. This was particularly important for younger patients who had to stay in hospitals.

The elements of care or services that people felt could be improved included:

- Food – a number of people reported that their families used to have to bring them meals from outside on a regular basis
- Access to more ‘modern’ equipment – some people said that in places where there was only one or two scanners (for example), they often had to wait – especially if one of the machines had broken down
- Access to different treatment and therapies – eg hydrotherapy, emotional support, physiotherapy
- Better communication about care – especially between teams

- Better wheel chair access on all sites
- Better social facilities eg TV, internet access

3.2 Initial views about the National Rehabilitation Centre

“It sounds absolutely great. Everything in one place – and all the equipment would be new probably. Why wouldn’t you want that?”

“Having access to specialist staff and the latest research is really important. I would feel my husband was really getting the best care”

“I’ve seen the Defence place on the news – it looks really good. And everyone knows that the military has all the latest treatments”.

“It sounds too good to be true – what’s the catch?”

Most participants thought that the idea of a National Rehabilitation Centre was really good. Some were particularly taken by the idea that patients in the East Midlands would have first access to it.

The most attractive features appeared to be the ability to access high quality care, treatment, equipment and expertise all in one place. Both patients and carers felt this would speed up the process of rehabilitation. Patients at the Major Trauma Centre and patients with musculoskeletal injuries particularly highlighted the importance of access to high quality physiotherapy and related services. Access to hydro-pools, cycle tracks and gym equipment were particularly important to them.

People also felt that having a national training and education centre located at the same site as well as research facilities could only benefit patients in the long-term since they would have access to both expertise and research innovations first.

Some people who had heard of the Defence Medical Rehabilitation Centre and had followed its development on the news mentioned the attractive setting, the latest equipment (including a golf course) and were pleased that the proposed National Rehabilitation Centre would be aligned to this.

There was some scepticism though from a few participants. Some felt that there had to be some hidden costs for patients/their visitors and/or that patients would ultimately

bear the cost of this in the long-term. Others felt that money allocated to this should be spent on improving existing rehabilitation services that patients were familiar with.

3.3 The impact of the proposals on patients

“I only live down the road so it wouldn’t be as convenient for me or my family, but if it meant I got access to the latest treatment, the best doctors, and get better more quickly then I definitely would be willing to travel further for my care”

“I would want to know that the staff that look after me here would be at the new place – trust doesn’t get built overnight. I wouldn’t go there if there were new teams.”

“It would be a tragedy if this place had to close down because of the new Centre”.

The main impact or concern of the proposals raised by participants was losing access to trusted and familiar staff. Many people were concerned that the people currently providing their care would not transfer to the new Centre and that they would have to be treated by new unfamiliar teams. Questions were also asked about what would happen to existing rehabilitation services once the new National Rehabilitation Centre was established.

Travel was not an issue for most patients – for some it would be closer than where they were currently accessing services and others were willing to travel a bit further to get access to high quality care. Travel and location was an issue for others – some lived very close to their current services so travelling to the National Rehabilitation Centre would be more expensive and inconvenient for them. Others felt that it would be very inconvenient for their families / carers. They wanted assurances that provision for families to stay with the patient (especially younger patients) were available and that costs such as parking and travel could be subsidised.

Patients with multiple conditions (eg head injuries and orthopaedic needs) who currently had to see different doctors and support teams felt these proposals would be of huge benefit to them and their carers and would save them a lot of time currently spent “waiting and travelling”.

People wanted more detail or clarity about a number of other issues, in addition to those previously mentioned such as the future of current services and staff, including:

- The types of services patients could access
- The number of extra patients seen and the number of extra staff available
- Whether children and young people would have access to educational support
- How the Centre would become financially viable in the long-term

4 Conclusions

It is clear that patients really value the rehabilitation services that they have received from the NHS. In particular, the quality of care and attention provided by staff appears to be most appreciated by all patient groups.

Most patients were very receptive to the proposals for a National Rehabilitation Centre as outlined in the *Transforming Rehabilitation Services* paper. The idea of receiving care “all in one place” was appealing as well as having access to the latest technologies and therapies. The biggest concern for many was losing access to the personal connections they had made with staff who had cared for them. People wanted reassurances that these members of staff would still be in their roles as part of their changes and / or could have access to them. The idea of building new relationships with new teams was a bit daunting for some.

There was some scepticism expressed by a small number of participants who did not think that the plans would be viable in the long-term and that existing services should be invested in instead.

Most people were willing to travel further if necessary to access better services. However, they wanted to make sure that it would also be easy for their families to visit them and affordable for them. This was a particularly important issue for younger patients.

The small number of people who felt they would not travel further to access services at the proposed National Rehabilitation Centre cited convenience and familiarity with the services they received by people they trusted as the main reasons for not doing so.

Many participants recognised the opportunities that having one centre with access to the latest research and expertise provided by a national education centre presented particularly in terms of improving their health outcomes more quickly.

Some people, while supportive of the proposals, still felt that “it sounded too good to be true”. It was felt that more information was needed about:

- the types of services patients could access
- clarity about what would happen to existing services
- the costs to the patients and their families / visitors
- how the Centre would be financed in the long-term not just the short-term.