Improving adult rehabilitation services – a case for change?  
Engagement with service users, and the commissioning and provider community

A process of engagement to provide a vision of ‘good’ rehabilitation as defined by the service user's experience and commissioners’ and providers’ identification of the enablers and barriers to providing such rehabilitation.

Inductive methodology for gathering intelligence

Service users’ reference group (SURG) [16]

Multi-sector provider and commissioner reference group (PCRG) to draft vision [105 of which 25 remote]

Trained data gatherers (graduating healthcare professionals) [12]

Service users interviewed [73, 10 of which were interviewed in a focus group] (Appendix I Patient Interviewee Profile Summary)

Data collection through semi-structured interview and focus group and thematic analysis

SURG and PCRG events to: (Appendix ii and Appendix iii Participant Profile Summaries)

- triangulate data from patients, providers and commissioners (Appendix iv The service user’s experience of rehabilitation & Appendix v Providers’ and commissioners’ issues to be addressed to deliver ‘good’ rehabilitation)
- cross-examine vision
- debate and identify enablers and barriers to delivering services that address the characteristics of ‘good’ rehabilitation
I would have expected to be sat down and given options. I think I have managed to get the services I need through my own persistence and endeavours and I wonder if another person in the same situation, who was a bit more passive, what would they have got?

One size fits all approach doesn’t work, it’s got to be tailored to the individual especially if services are trying to get that person back to normality because everybody’s normality is different so it has to be tailored to the individual.

Now I am back in primary care I need support sometimes but I feel the door has been closed.

So many people are looking at me in bits, no one looking at me as a whole total person.

The carers came in, started to cook my meal. I had to get undressed and needed to help as couldn’t breathe. They said it wasn’t in my care plan so they couldn’t help. They gave me my meal but I had to sleep in my clothes.

I am well educated and had mental capacity and a wife to support and luck on my side. Especially finding the gym. There was very little signposting about services.

So we set goals for me to achieve ... they were always happy to help me with any information.... Actually felt the whole programme was tailored towards me not just the condition I had.

A sample of the service user’s experience

Taken from interviews across service users with a range of rehabilitation needs (Appendix i)
A vision of ‘good rehabilitation services’ generated from triangulation of data from service users, providers and commissioners

1. The patient, their expectations and outcomes are at the centre – Services are user led with shared decision making focused on enhancing and maintaining quality of life and enabling a meaningful life as determined by the individual

2. The relationship between patient and provider – There is an honest relationship between the patient and service provider built upon joint responsibility and a shared process. Service providers offer education and facilitation to enable effective patient-directed care and self-management

3. Access to services – There is easy, open access, including self-referral, to services. Patients are able to choose the timing, model and place of access according to their specific needs. Wherever the patient is on their ‘journey’ they can jump on and off the pathway according to need. The location of services is likely to be as local to the patient as possible, but will be guided by the individual’s goals and outcomes. Services may be delivered anywhere that will meet the needs, goals and outcomes of the individual patient (e.g. home, community, workplace, sports clubs, gym, school, hospital and specialist centre) but will be safe and within realistic geographical reach of the service providers

4. The business model – The business case for the delivery of rehab is framed on a clear definition of ‘rehabilitation’ based on a robust rehab data sets, evidence based practice all informing outcomes for individuals, organisations and populations: this will include robust financial and risk management plans to support the whole pathway of integrated outcomes addressing service users’ ‘needs’ rather than ‘disease’ and enable the use of personal budgets. Commissioners will utilise this to procure outcomes clearly identified in contracts and performance frameworks integrated around the individuals journey

5. The pathway – The pathway is integrated across health, social care, local authority, private and voluntary providers and the community. A ‘system navigator’ function signposts patients to services according to their specific needs. The pathway is designed around the patient and coordinated to flow as a smooth journey through prevention, acute admission, specialist tertiary services, community services, primary care and vocational/social integration, with the local population/neighbourhood playing a supportive role and offering assistance with reintegration. The pathway may include end of life care, family carer support and bereavement services

6. The model of service – ‘Rehabilitation’ is offered seven days a week by a multidisciplinary, multi-agency team defined by the patient’s needs, goals and outcomes. Duration of the service is determined primarily by the agreed outcomes rather than diagnostic condition. In addition to therapeutic intervention, the model will include information, advice, education and health promotion for patients to enable self-support. There will be a focus on access to mainstream services and participation in community activities/occupation as agreed with the patient. The team around the patient will be underpinned by safe practice and strong governance and will include both generalist rehab staff and specialists, including psychological support. Services can be provided for mixed groups of patients with different conditions but similar needs and goals

7. The evidence base – there is a robust body of evidence that will focus on outcomes of rehabilitation and reablement. It will not be defined by disease group and will take account of the impact of comorbidities. The evidence base will be compelling and support the commissioning of personalised rehabilitation

8. Communication between all providers and service users – There is sharing of knowledge and information using a full range of social marketing, IT and online solutions to support understanding between the full range of service providers and service users; to enable effective planning of pathways and to promote multidisciplinary and multi-agency learning and training

9. The workforce – The workforce will utilise a broad range of personal and professional skills including those of service ‘navigators’, specialist professionals, reablement workers, carers, voluntary services and members of the community. This workforce will offer a breadth and depth of skills with extended scope of practice so that people’s needs are met flexibly with maximum quality of care. Professional leadership within teams will ensure quality standards of care whilst senior leadership from a breadth of ‘rehabilitationists’ at a policy level locally, regionally and nationally will ensure development of the rehab evidence base, and effective commissioning of quality services and the future workforce
Enablers and barriers as described by providers, commissioners and service users

Barriers
1. The system is built around disease specific medical models and does not take a whole person or system approach
2. The culture is not customer focused and the patients’ needs and goals are not central to how services are designed, delivered or commissioned
3. Finding and accessing appropriate services is difficult for the individual. Referrers within the system are not sufficiently familiar with available rehabilitation services and their potential
4. Services are commissioned in time delineated blocks rather than for outcomes
5. Cross system commissioning is constrained by a lack of compelling business plans for rehabilitation in addition to financial complexities such as costing systems which do not define rehabilitation, which make it difficult to extract rehabilitation from disease based pathways and to monitor the outcomes of rehabilitation
6. The evidence for rehabilitation (to support better commissioning) generally focuses on
   a) individual conditions and the acute stage
   b) is not focused on where it is required to support change, that is, outcomes and reablement (taking account of co-morbidities)

Enablers
1. A rehabilitation clinical champion at a strategic level to provide leadership, an expert overview and influence the focus of research
2. A clear definition of rehabilitation for commissioning, unbundling of disease specific tariffs, development of rehab bundles with agreed costs, commissioning of services against integrated outcomes and use of personal budgets to meet the needs of the individual not just the condition
3. Good quality, shared rehab data sets based on need, activity, demand and outcome
4. A navigation function building on existing models of good practice in the voluntary, social and health sectors. Navigation will range from effective use of new technology and shared information systems about services and outcomes that the individual can access, through to a navigation role supporting an individual with more complex needs. This will enable:
   a) Joint care planning allowing service users to exercise informed choice over the building blocks and location of the services in their pathway that takes account of both clinical and personal outcomes.
   b) Planned transitions between rehabilitation, reablement and social care
5. Rigorous peer review to drive up quality and spread improvement in integrated service delivery
6. Service users involved in the planning, monitoring and commissioning of rehabilitation services
7. A workforce able to work with service users to agree individual goals and outcome measures. It will be built around competences required to deliver rehabilitation, not professions. Customer care is central to that delivery both in the skills of the workforce and the infrastructure such as easy access and appointment systems