Northern Children's Rehabilitation Board

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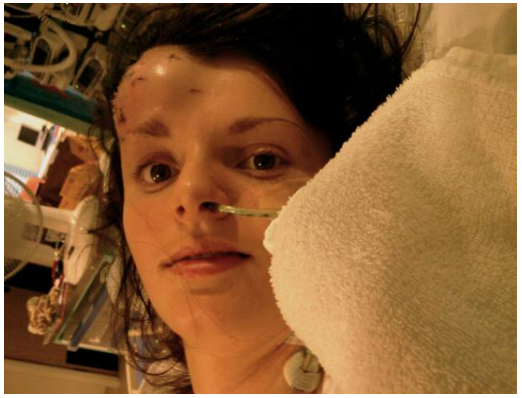
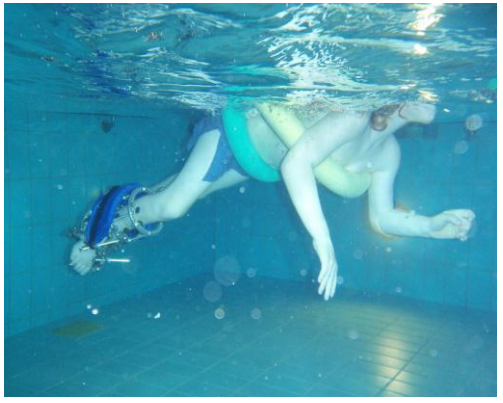
ROYAL MANCHESTER CHILDREN'S HOSPITAL

Central Manchester NHS University Hospitals NHS Foundation Trust

Children and Young People's Rehabilitation Project





Information Gathering

- Working groups with community, hospital and education
- Identified gaps in services
- Patient and parent involvement
- Literature review

Confirming what we thought

Patient Feedback

"I was put on a side ward with three young toddlers and three creepy Dads. One introduced himself by saying he had only just got custody of his child as his wife had stabbed someone and another only came to see his child when social services were coming".

"For some reason the government will not let a patient be home schooled at the same time as going into school for short visits".

"I became very isolated as my school friends had lost interest in me. None of them came to visit once I was home and I became very used to the company of those much older".

"I was even told that 'perhaps the school wasn't for me'"

"Three years after the accident and I was still under three consultants following issues related to the initial injuries"

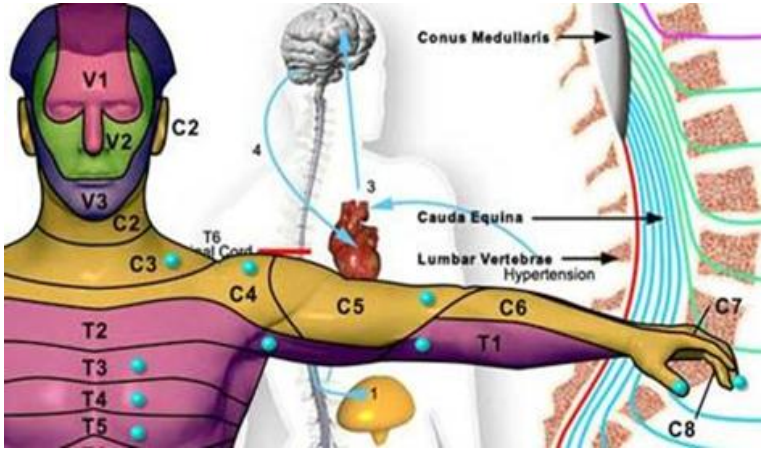
'I am supporting a young person with restricted height who is going to mainstream secondary school in September. Standing at a desk on the floor the ideal height would be 45cm high. Working at this height the young person would be safe but may be socially isolated from her peers and this may be a trip hazard to others..'.

"We had tried to get me back to school much earlier but I was told I could not attend school in my wheel chair as I was a fire risk!"

"My OT assessment at the hospital had resulted in me coming home without a wheel chair as apparently these could only be given to those who really needed them and I didn't class as that. Had it not been for kind neighbours I would have been housebound"

What does the literature say about children's rehabilitation needs?

Case Study



- 11 year old girl
- Spinal Cord sporting injury at C7
- Transitioning into high school
- Medically fit for discharge 6/52
- Paralysis in the legs & torso
- Ability to extend shoulders and arms but limited dexterity in fingers

Rehabilitation Prescription

- Specialist spinal injury rehabilitation
- Access to full time education
- Social and peer support
- Home adaptations and equipment

Requirements clear at 48 hours post injury

Current provision
10 weeks post stability

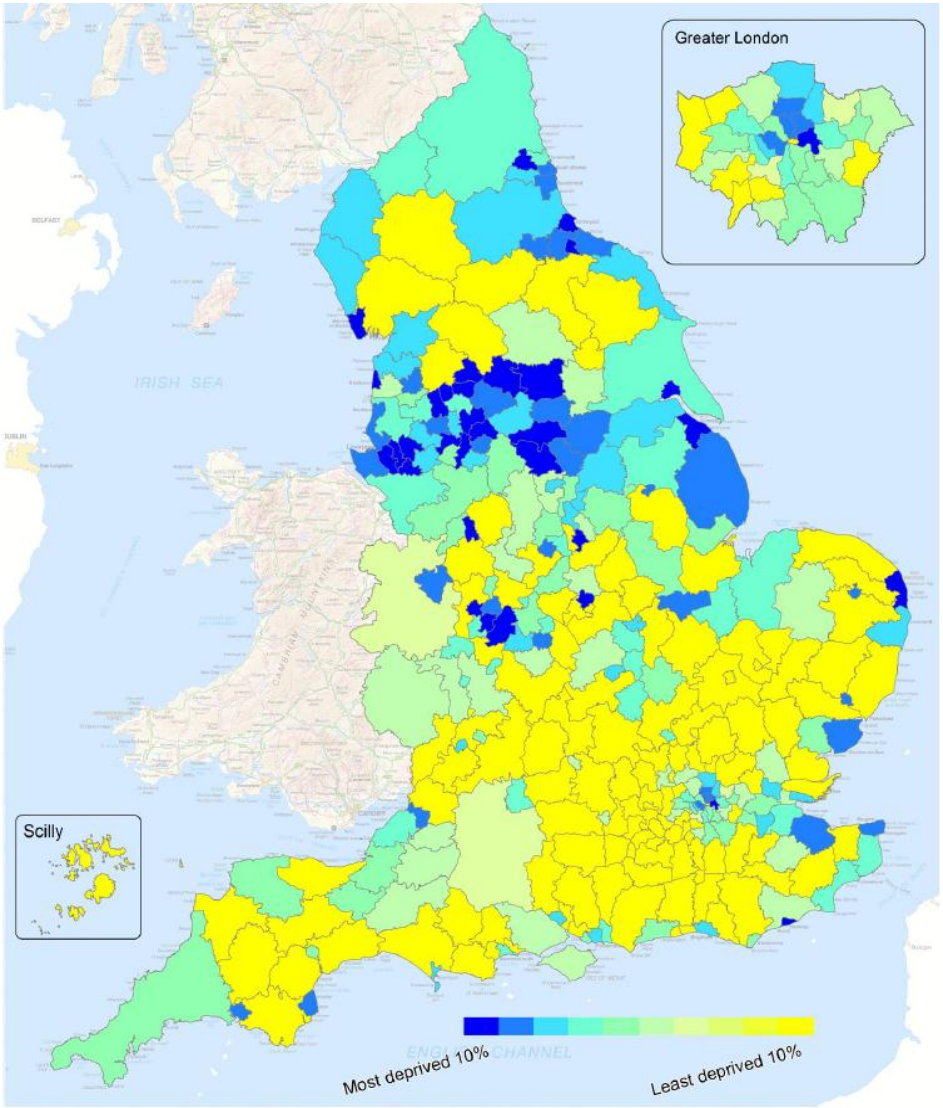
- Tx to DGH local to SCI centre
- Specialist rehabilitation in SCI Centre
  - 30 mins transfer to SCI centre
  - Multiple training needs for nursing staff on DGH ward-delay transfer
  - Hospital tuition – approx. 1 hr. a day
  - Lack of contact with peers and family
  - Patients home closer to SCIC

Still has no discharge date for home

Why Children?

- **25% of population**… and increasing
- **Annual Mortality** compares poorly to comparative European Nations
- "**Children lose out to demands of adults in NHS**" – failure to provide more than "mediocre services" argues **Sir Ian Kennedy**, 2010
- **Major Public Health issues** – accidents, obesity, maternal health during pregnancy

Why the North?
Indices of Deprivation 2015



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Middlesbrough, Knowsley, Kingston upon Hull, Liverpool and Manchester are the local authorities with the highest proportions of neighbourhoods among the most deprived in England

Point Prevalence Study

- 26 children medically fit for discharge
- Total of 4218 bed days
- Longest LOS = 322 days

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Opportunities for care closer to home

Personal and Economic Benefits of Improving Rehabilitation Services

Personal/family impact

- Discharged home earlier
- Return to education
- Maintain peer group
- Economic benefit to family

Economic impact

- Decreased long term health/therapy needs
- More likely to contribute to the economy
- Chance of better recovery?

The Vision

We will design services that provide for the individual rehabilitation needs of the child or young person and their family

Project Launch

Local Governance, National Learning

North West Paediatric Trauma Rehabilitation Workshop-April 2014 & June 2016

Children's Rehabilitation Board established February 2016

Approved by clinical reference groups- Neurosciences and Major Trauma

NHS England

Endorsed by NHS England Programme of Care Boards (Women and Children)

Devolution and Vanguard opportunities

National Clinical Directors supportive of project

Scope

All acquired conditions including

- Acquired brain injury
- Acute spinal cord conditions
- Tumour/oncology
- Infection
- Vascular disease
- Trauma
- Burns
- Other acute events

Scope

Pathway: From onset of the condition through to achieving the lifelong potential

Target Population: 3.7 m children across the North of England.

Age: 0-18 years

Board Membership Representation

Commissioners, Networks

Social Care

Finance

Schools

Community

Children's Rehabilitation

Charities

CAMHS

Family, Friends

Health & Social Care Professionals

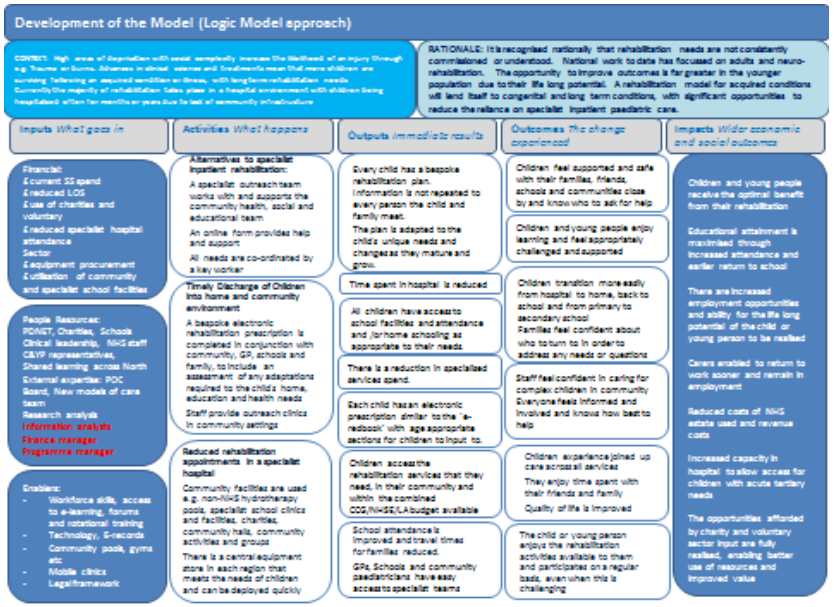
Equipment

Northern Board
Project Objectives

- Develop rehabilitation pathways to meet the needs of children and young people
- Develop outcome measures and explore research opportunities
- Use the ‘Vanguard Approach’ to allow the project to be replicated nationally whilst being flexible for local populations

Improve children’s long term outcomes following a life changing event

Logic Model



Development of a nationally replicable pathway looking at:

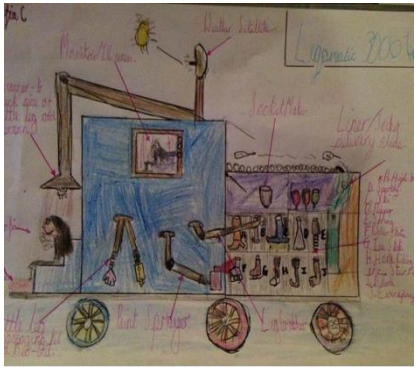
- Inputs — What goes in
- Activities — What happens
- Outputs — Immediate results
- Outcomes — The change experience
- Impact — Wider economic and social outcomes

Workstreams

Governance

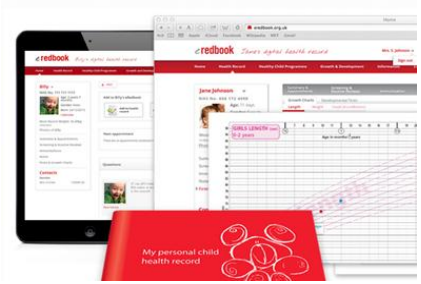
Equipment

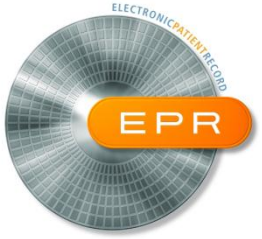
Pathways



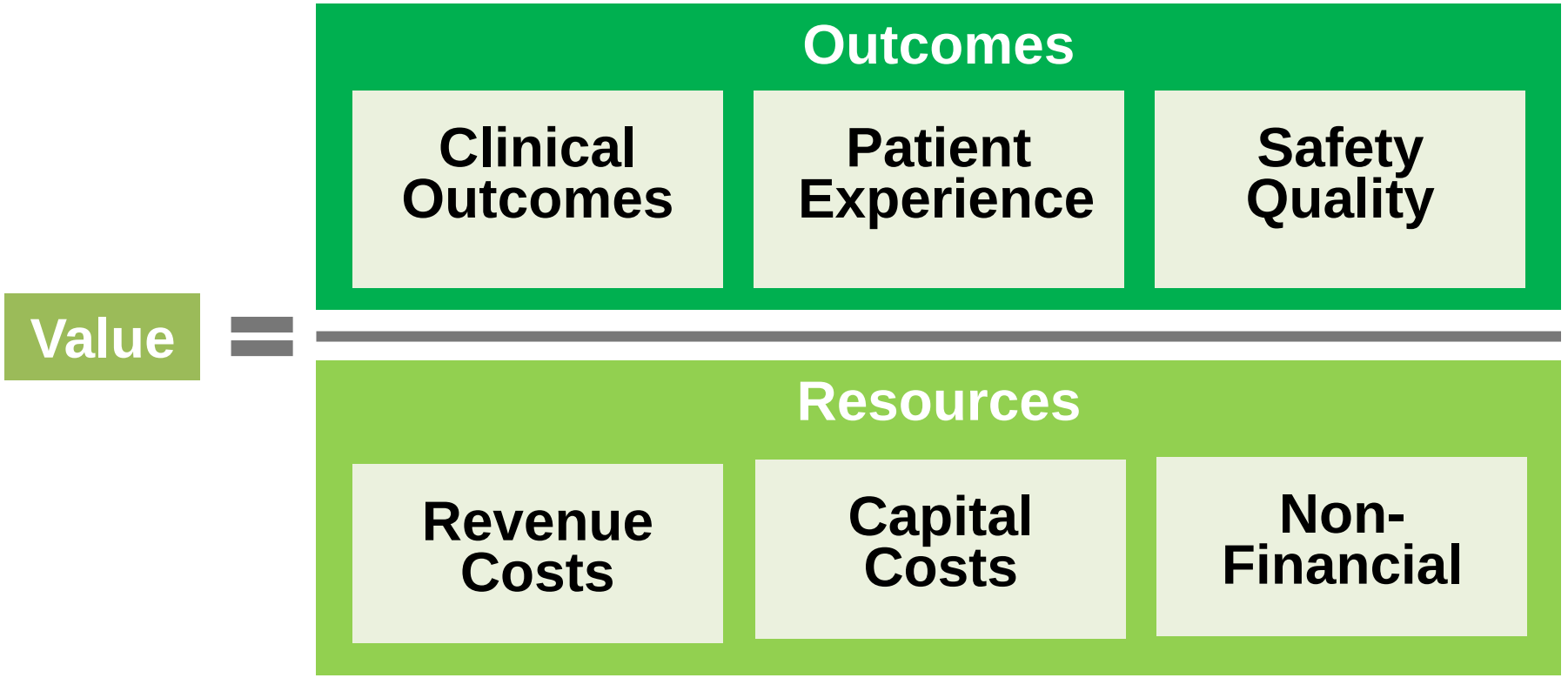
Early Supported Discharge

Technology





Value Equation



Network Board Priorities

- Establish governance structures
- Engage commissioner's
- Identify funding streams for project management and innovations
- Identify data collection methods – PROMs/PREMs, audit, dashboards

Work plan

- Review standards, recommendations and guidance
  - Sept ’16

- Pilot pathway
  - April ‘17 – March ’18

- Roll out nationally
  - July ‘18

What should this mean for our patient?

- Discharged home when fit with suitable equipment whilst awaiting adaptations
- Key worker
- Access to full time education
- Specialist rehabilitation in community with combined specialist outreach team/community services
- Support from third sector services

Thank you

Development of the Model (Logic Model approach)

CONTEXT: High areas of deprivation with social complexity increase the likelihood of an injury through e.g. Trauma or burns. Advances in clinical science and treatments mean that more children are surviving following an acquired condition or illness, with long term rehabilitation needs
Currently the majority of rehabilitation takes place in a hospital environment with children being hospitalised often for months or years due to lack of community infrastructure

RATIONALE: It is recognised nationally that rehabilitation needs are not consistently commissioned or understood. National work to date has focussed on adults and neuro-rehabilitation. The opportunity to improve outcomes is far greater in the younger population due to their life long potential. A rehabilitation model for acquired conditions will lend itself to congenital and long term conditions, with significant opportunities to reduce the reliance on specialist inpatient paediatric care.

Inputs *What goes in*

Financial:
£ current SS spend
£ reduced LOS
£ use of charities and voluntary
£ reduced specialist hospital attendance
Sector
£ equipment procurement
£ utilisation of community and specialist school facilities

People Resources:
PDNET, Charities, Schools
Clinical leadership, NHS staff
C&YP representatives,
Shared learning across North
External expertise: POC Board, New models of care team
Research analysis
Information analysts
Finance manager
Programme manager

Enablers:
- Workforce skills, access to e-learning, forums and rotational training
- Technology, E-records
- Community pools, gyms etc
- Mobile clinics
- Legal framework

Activities *What happens*

Alternatives to specialist inpatient rehabilitation:

A specialist outreach team works with and supports the community health, social and educational team

An online form provides help and support

All needs are co-ordinated by a key worker

Timely Discharge of Children into home and community environment

A bespoke electronic rehabilitation prescription is completed in conjunction with community, GP, schools and family, to include an assessment of any adaptations required to the child's home, education and health needs

Staff provide outreach clinics in community settings

Reduced rehabilitation appointments in a specialist hospital

Community facilities are used e.g. non-NHS hydrotherapy pools, specialist school clinics and facilities, charities, community halls, community activities and groups

There is a central equipment store in each region that meets the needs of children and can be deployed quickly

Outputs *Immediate results*

Every child has a bespoke rehabilitation plan.
Information is not repeated to every person the child and family meet.
The plan is adapted to the child's unique needs and changes as they mature and grow.

Time spent in hospital is reduced

All children have access to school facilities and attendance and /or home schooling as appropriate to their needs.

There is a reduction in specialised services spend.

Each child has an electronic prescription similar to the 'e-redbook' with age appropriate sections for children to input to.

Children access the rehabilitation services that they need, in their community and within the combined CCG/NHSE/LA budget available

School attendance is improved and travel times for families reduced.

GPs, Schools and community paediatricians have easy access to specialist teams

Outcomes *The change experienced*

Children feel supported and safe with their families, friends, schools and communities close by and know who to ask for help

Children and young people enjoy learning and feel appropriately challenged and supported

Children transition more easily from hospital to home, back to school and from primary to secondary school
Families feel confident about who to turn to in order to address any needs or questions

Staff feel confident in caring for complex children in community
Everyone feels informed and involved and knows how best to help

Children experience joined up care across all services

They enjoy time spent with their friends and family

Quality of life is improved

The child or young person enjoys the rehabilitation activities available to them and participates on a regular basis, even when this is challenging

Impacts *Wider economic and social outcomes*

Children and young people receive the optimal benefit from their rehabilitation

Educational attainment is maximised through increased attendance and earlier return to school

There are increased employment opportunities and ability for the life long potential of the child or young person to be realised

Carers enabled to return to work sooner and remain in employment

Reduced costs of NHS estate used and revenue costs

Increased capacity in hospital to allow access for children with acute tertiary needs

The opportunities afforded by charity and voluntary sector input are fully realised, enabling better use of resources and improved value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