

# Lessons learned from patient user groups

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# CCNRT

Specialist community neurorehabilitation focusing on:

- Managing personal care
- Mobility
- Domestic activities
- Return to work and leisure activities
- Communication
- Memory strategies
- Coping with disability
- Information and education
- Access to local facilities





*Pablo Picasso  
Reclining Nude, 1969  
Private Collection  
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# Why have a user group?

- Health and Social care Act 2003
- Standards for better Health 2005/8
- To provide a quality service
- To improve outcomes
- To improve experience
- To move away from targets



# Why have a user group?

- To manage expectations
- Identifies improvements to the service
- 70% of patients responding to questionnaire agreed it was a good idea
- Empowers the users to make a difference
- Users engaged in a different way
- Two way process
- Actually quite fun



# How did we set them up?

- Started in February 2008
- Questionnaire sent to 100 discharged patients
- Identified topics they would like to discuss
- Up to 22 patients and carers attend each group



# What was discussed?

- Discharge planning
- Transport arrangements
- Information about condition
- Therapy groups
- Carer involvement
- Discharge reports
- Website
- Patient questionnaires



# What are the lessons learned?





# What are the lessons learned?

## Discharge planning

- More therapy please...
- Comprehensive discharge pack
- Point of contact in case of need
- Gradual discharge
- Review



# What are the lessons learned?

## Transport

- Patients understood why they needed to be ready early
- More understanding about driver constraints
- Ambulance service encouraged to give patients extra time
- Generally an excellent service



# What are the lessons learned?

## Information

- Patients and carers do not take in what is given in hospital
- Repeated information needs to be given across the pathway
- Follow up after hospital not explained
- Patients and carers need specific info read with them
- Message book to communicate with families where appropriate.



# What are the lessons learned?

## Carer involvement

- Some carers value attending sessions
- Carers group useful
- More written information required



# What are the lessons learned?

## Therapy groups

- Further info before attend the group
- Smaller therapy groups (4) better
- Enjoy Wii group, even as a spectator
- Active hands group good for socialising as well
- Good for peer support
- Encouraging progress
- Follow up group



# What are the lessons learned?

## Discharge reports

- Positive comments about content
- Easy to understand
- Useful summary
- Goal achievement needs to be discussed
- Further info about what to do next
- Good for GP's



# What are the lessons learned?

## Website

- Patients already know about CCNRT
- Waste of time for those that cannot access
- Simple and clear
- Good for GP's
- More links to other services
- Ideas for post discharge



# What are the lessons learned?

## Questionnaires/outcome measures

- Part of discussion, rather than handed out
- Up to 6 forms acceptable
- Need to understand reason
- Need feedback on results





## What are the problems?

- Inequitable as we cannot offer transport
- Some patients unable to participate fully
- Limited space
- Should be run by outside agent perhaps
- Very positive feedback usually



## Next steps

- Last group met on 17<sup>th</sup> September – report to be written
- Acute services involved with community team groups
- Individual interviews of patients to help us understand the pathways





Here for you

## Latest feedback

- *“we did not receive much information about stroke in the hospital”*
- *“Would have liked a leaflet explaining what causes strokes and it would be helpful if someone went through the leaflet as not at that stage able to read it”*
- *One user group member volunteers at Mayday and reported “the problem with Mayday information leaflets could be they are put on the side out of the way and patients physically cannot go to reach for them”*
- *“I had a one-to-one explanation (about stroke) in a quiet room at St Georges which was very helpful”*
- *“I was put on medication with no explanation or information from Doctor”*
- *“Health staff should check a patient’s hearing, I didn’t have access to hearing aid, staff assumed I didn’t understand because of my stroke”*



Thank you





Here for you



Here for you



Here for you