

**Primary Care Trust
Rehabilitation and Intermediate Care**

A Listening Event

Report

2 November 2007



Newcastle **NHS**
Primary Care Trust

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1. Background

On 2 November 2007 over 50 older people and carers gathered at Disability North for a Listening Event on Primary Care Trust (PCT) Rehabilitation and Intermediate Care Services in Newcastle upon Tyne. The event was organised jointly by PCT Rehabilitation and Intermediate Care Services and the Quality of Life Partnership.

The purpose of the event was to inform people about new developments in PCT Rehabilitation and Intermediate Care Services, in particular the introduction of a single point of access. It also provided an opportunity to reflect on progress since the last Listening Event which was held in 2001. Most importantly, it gave older people and carers an opportunity to feedback about their experiences of services and to put forward ideas for improvements.

Invitations were sent out to people who had recently used PCT Rehabilitation and Intermediate Care Services and their carers as well as to key voluntary organisations working with older people and carers. The majority of the people who attended came via the Stroke Services.

Staff from the different services which make up PCT Rehabilitation and Intermediate Care also attended to listen first hand from older people and carers about their experiences of their services.

In addition to the event, PCT Rehabilitation and Intermediate Care Services sent out a questionnaire to people who had recently used their services. The results of the questionnaire have been incorporated into this report.

2. Feedback from the Listening Event held in 2001

Vera Bolter (Elders Council of Newcastle) gave the background to the Listening Event on Rehabilitation and Intermediate Care

Services held in 2001, which involved older people visiting 15 different services and interviewing staff. The main recommendations from this work were:

- The range and diversity of the services were welcomed, but some of the services then have since closed down or changed.
- Access to Rehabilitation and Intermediate Care Services; it was noted at the time that there was not equal access for all e.g. people with mental health problems seemed to be excluded and there was low take-up from members of black and minority ethnic communities.
- Information about the range of services needed to be improved for everyone, including professional workers, older people and carers.
- Carers need to be fully involved and supported in their caring role.
- Listening to older people and carers needs to continue and to be built into service development.

Vera noted that new services have come into existence, improvements have been made to access to services, support to carers and information. Vera called for improvements in the way in which issues raised by older people and carers are taken forward in constructive dialogue with service providers.

3. Key Issues

In general, people expressed satisfaction with PCT Rehabilitation and Intermediate Care Services, with several groups referring to excellent and very good services. *'Excellent care – looked after the whole person. It's the little things which make the difference.'*

Older people and carers were invited to make recommendations on how things could be improved. The following suggestions were made:

3.1 Walkergate

Although it was noted that the services at Walkergate Hospital are not provided by the Primary Care Trust and do not form part of PCT Rehabilitation and Intermediate Care Services, feedback from the event clearly stated that Walkergate Hospital was not found to

provide a therapeutic environment and does not have an active rehabilitation programme. *'No rehab input over 4 week stay.'*

3.2 PCT Rehabilitation and Intermediate Care Service Single Point of Access

The single point of access was welcomed, but the following points were made:

- It needs to be well publicised and staff trained to use it;
- It needs to be adequately resourced to carry out timely assessments, otherwise it could be a bottleneck;
- It has the potential to also serve as a single point of access to advice and information (see point 2.3 below).

3.3 Information and Advice

Information and advice both about services but also on how to manage lifestyle changes was a very strong point which was raised by several groups. The following recommendations were made:

- Staff need to understand the importance of their information-giving role and be proactive in giving out information to older people and carers *'I had to ask questions all of the time.'* *'Things need to be explained more. 'I was told I was going to x service, but not told what to expect.'* *'no information from the doctor'.*
- There is a need for a single point of access for information and advice, in particular after discharge (see point 2.2 above).
- Older people and their families need information about the impact on their lifestyle and how to manage *'I was not told how it would affect my husband.'* *'Early and appropriate information is needed especially at point of diagnosis or when in contact with an appropriate professional.'* *'Would have liked support from the team to inform/educate the family about the effects of stroke and the impact on lifestyle'*
- Accessibility of information needs to be taken into account (e.g. hearing or sight loss; impaired cognition; language barriers).
- Patients and carers need information at the appropriate time and particularly on discharge.
- Information/education on prevention.

All those who attended the event were given information about Information NOW (www.informationnow.org.uk) which is Newcastle's Older People's Website and contains a wealth of information about local services, as well as signposting people to other sources of information. Recognising that some older people cannot access the internet, staff in all services and families are encouraged to access this website on behalf of older people to help them to access the information they need.

3.4 Communication between services

Several groups highlighted the need for improved communication between services, especially between acute and rehabilitation services. *'Better co-ordination between acute care (Hospitals Trust) and community care (PCT).'*

There were also examples of poor discharge, in particular over a Bank Holiday – *'I was not told what would happen at point of discharge.'* *'More information should be given to patients and carers on discharge.'*

3.5 Follow-up/Review

There were several requests for improved follow-up and review. These included:

- Reviews to assess changing needs *'a system of reviews or re-referrals to assess changing needs'*;
- Reviews to assess need for equipment to check whether the appropriate equipment has been provided and whether it is being used correctly;
- The need for follow-up for people who are discharged to a nursing home but still have potential for improvement.

3.6 Support for Carers

The need for a range of support for carers was raised:

- More carer support groups;
- Widening access to carer support groups to other family members;
- Better information, advice and training for carers;
- Assessments of the carer's needs – *'the carer needs professional care also'*;

- Greater consistency in care service provision - *'we never knew who was coming'*.

3.7 Staffing levels and access to therapy

There were several references to staff being overstretched and therefore not being in a position to give patients and carers sufficient care and attention. *'Staff are rushed and don't read notes.'*

The limited availability of therapy services was also commented on. *'Paid for private physiotherapy in the end.'*

3.8 Access to on-going support and activities

One of the most powerful message from the event, was how to enable people, particularly those who have suffered a stroke, to access informal networks, social activities, groups and clubs.

The PCT Stroke Discharge Team was particularly commended for the quality of its service. However, many people felt that the service was withdrawn too soon, leaving them without emotional support and access to activities. *'Stroke Discharge has to pull out too quickly. You feel abandoned and isolated.'*

The Different Strokes group was also commended for the support it provides – *'You need to take responsibility for your own recovery, but really benefit from external support.'*

There was a recognition that older people and carers have a role to play in helping to organise support groups and activities – *'organise fundraising events involving stroke survivors and professionals – a common goal. Combine this with raising awareness of stroke.'*

Questions were also raised about how to involve stroke survivors in general activity groups and how to ensure that tutors/group leaders were trained appropriately.

3.9 Involvement of older people and carers in service design

Older people and carers welcomed the opportunity to give their views in an informal setting rather than through questionnaires or surveys.

However, having given their time to this event, older people and carers stressed the importance of being able to follow up on any actions taken as a result of their recommendations.

Action for Health – Senior Citizens in Newcastle, which also acts as the Health and Social Care Group of the Elders Council, is a group of older people and carers which meets monthly. Regular reports to Action for Health on progress is one way in which on-going feedback will be given. Any member of the Elders Council is welcome to join Action for Health. For further details contact Vera Bolter, Elders Council of Newcastle on 233 0200.

3. Next steps

The following work will now take place to take forward the recommendations and ideas from this event::

- Incorporate the recommendations from the Listening Event and the questionnaires into the 3 month evaluation of the Single Point of Access service.

Action: PCT Rehabilitation and Intermediate Care Single Point of Access Evaluation Co-ordinator

- As part of the evaluation, explore the issue of self-referral to the Single Point of Access and whether the Single Point of Access can also provide an advice and information service.

Action: Single Point of Access Evaluation Co-ordinator

- Raise staff awareness of the importance of information giving and promote the involvement of older people and carers in decision-making.

Action: Lead OT – PCT Rehabilitation and Intermediate Care Service

- Raise issues re identified gaps in service with Primary Care Trust Management:
 - Poor communication between services, in particular between acute and community services;
 - Therapy input discontinued too soon, therefore limiting potential for full recovery;
 - Lack of input into care homes, limiting potential for recovery.

Action: General Manager – PCT Rehabilitation and Intermediate Care Service

- Feedback information from the event to Newcastle Community Stroke Services Co-ordinator and explore potential for ongoing support for patients and carers.

Action: Lead OT – PCT Rehabilitation and Intermediate Care Service

- Work with carers' organisations to increase availability of support, ongoing advice and information and mutual support groups.

Action: Quality of Life Partnership Co-ordinator in partnership with Carers Centre Newcastle and others

- Improve provision of community-based activity groups and facilitate the inclusion of people who had suffered strokes in general activity groups by providing training and support to tutors and group leaders.

Action: Quality of Life Partnership Co-ordinator through the Active Ageing Programme

- Write to Len Fenwick (Chief Executive of the Newcastle Hospitals Trust) re Walkergate and copy letter to Manager to Rehabilitation and Intermediate Care Services.

Action: Elders Council of Newcastle/Quality of Life Partnership

- Include key issues arising from this event in the review of Aim 3 [Enjoying emotional, physical and mental wellbeing] of *Everyone's Tomorrow* – Newcastle's Strategy for Older People and an Ageing Population.

Action: Quality of Life Partnership Co-ordinator

- Provide a 6 monthly feedback report to Action for Health – Senior Citizens in Newcastle.

Action: Lead OT – PCT Rehabilitation and Intermediate Care Service

4. Contact details

For further information about this report and on-going work contact:

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