Acquired Brain Injury Forum for London (ABIL)

www.abilondon.org.uk

Comments by ABIL on the consultation document 'The Shape of things to come. Developing new, high-quality major trauma and stroke services for London'

1. Acquired Brain Injury Forum for London (ABIL)

ABIL is a group of front-line professionals, commissioners, survivors of acquired brain injury (ABI) and carers working to advance the brain injury agenda across London. It was established in March 2007, and currently has 140 members (with a total distribution of 276). It is concerned with ABI of all causes, whether traumatic or non-traumatic, and thus brain injury caused by open or closed head injuries, strokes and other vascular events, and brain infections or tumours.

2. Our comments

Our comments mainly relate to the Major Trauma proposals, although some reference is also made to the needs of stroke survivors, some of whom will have needs broadly similar to those of people sustaining a brain injury after major trauma.

We generally welcome the Major Trauma and Stroke proposals as representing improved services at the acute stage, which should lead to reduced mortality and better initial outcomes for survivors. However, we have serious concerns on a number of counts, which also need to be addressed urgently in order to ensure the best overall outcomes in the long-term for these patient groups.

3. Journey time from scene of trauma to arrival at Major Trauma Centre (MTC)

The target journey time from the trauma scene to the MTC is quoted as 45 minutes. For a serious head injury, the first hour - from time of injury - is very important (the 'golden hour'). Since it could take considerable time to extricate a person from the scene of an accident, this could mean that the time from the actual injury to arrival at the MTC could - in some cases - be well in excess of an hour. We ask therefore why a shorter target journey time - possibly 30 minutes – has not been chosen. This could have implications for the number and location of MTCs.

4. Guidelines for 'triage' at the scene of the trauma (and expertise of paramedics)

The 'definition' of major trauma currently used lacks clarity. As a result, many people who have sustained a significant but isolated head injury will not be regarded as major trauma patients, for example, if their GCS (Glasgow Coma Score) is greater than 8 and/or their ISS (Injury Severity Score) is less than 15 (which would be the case when there is a head injury and no other major injuries).

We understand that this matter is subject to discussion, but emphasise that if serious isolated head injury is not rated as requiring major trauma services, patients will remain at risk of preventable death and disability. We look forward to the formulation of

evidence-based guidelines for assessment at the scene of the injury so that people with serious head injuries are not taken initially to Trauma Centres (A & Es), and then have to be transferred later to MTCs, resulting in loss of valuable time after injury.

We also emphasise the need to make public explicit guidelines for the training of all paramedics attending a major trauma scene, including mechanisms to update those guidelines and each individual's training.

This may also have implications for the number of patients treated by MTCs and thus the number of such centres needed.

5. A & E departments - concern re expertise and facilities

Our understanding is that every A & E department will contain a Trauma Centre, and thus be part of a Trauma Network. Concern has, however, been expressed that, with the establishment of the MTCs, key expert staff currently working in major A & E departments could be attracted to MTCs, with a resultant deskilling of A & E departments. Also, A & E departments could be downgraded in terms of availability, for example, of CT scanners and radiography staff.

The need for expert triage, with rapid access where necessary to CT scanning - for people who present at A & E after a head injury - is essential, since what might appear at first sight to be a 'mild' injury may in fact be much more serious (cf. the recent tragic death of Natasha Richardson). In fact, there is often no direct correlation between 'severity' of injury and longer term outcome. There is also need for improved guidance and advice, and follow-up procedures, following MTBI.

These are matters which will need to be addressed by the management of the Trauma Networks - in terms of workforce planning and equipment availability. We would like to be assured that the new arrangements will lead to better services and improved outcomes for all who sustain a head injury, whatever the apparent 'severity' of their injury.

6. Estimates of annual number of major trauma patients on which the proposals are based

The figure used for planning purposes is, we understand,1600 - but 2500 has been quoted elsewhere. Leading on from our comments (4 - above) about guidelines for triage at the scene of the trauma in respect of head injury, which represents about 60% of all major trauma cases, we ask whether the actual numbers of people needing services from MTCs after a head injury might be significantly higher than current estimates suggest. We suggest that further consideration be given to the numbers on which the proposals are based.

7. Neurosurgical expertise

There are some highly specialised neurosurgeons currently employed in Neuroscience Centres which are unlikely to be designated MTCs, for example, the National Hospital and the Royal Free Hospital. How is such expertise to be effectively utilised in the new arrangements?

8. **Follow-on services for major trauma (head injury) and stroke survivors**

We are concerned that there is little mention of the rehabilitation and support needed by major trauma and younger stroke survivors following acute treatment.

How is the provision of these services to be addressed? What additional capacity is required, and what systems need to be put in place to ensure that patients can travel in a smooth and timely way along care pathways?

These are issues crucial to long term outcome for survivors of serious head injury and for younger survivors of stroke and other vascular injuries such as subarachnoid haemorrhage. Stroke is largely a disease of older age, and this is reflected in the rehabilitation services provided after stroke. However, approximately 25% of stroke survivors are under 65, and 10% under 50 - that is, about 3-4000 and 1000 people, respectively, in Greater London each year. Many of these patients have complex needs similar to those of patients who have sustained serious head injury. They require a range of interventions at different stages of their journey, which include:

- Specialist acute inpatient rehabilitation. Rehabilitation should be started acutely after vascular and traumatic brain injury to prevent avoidable deficit. Organised acute rehabilitation after stroke will be provided by Stroke Units, but there is little in Greater London after serious head injury, none after major polytrauma, and no plans in the current proposals to address this gap in provision. Failure to provide a solution to this problem will squander gains made as a result of acute surgical and medical treatments in MTCs. How is a solution to this major gap in service provision to be found?

- Specialised early inpatient neurorehabilitation. Currently a pan-London Consortium of PCTs funds such rehabilitation after ABI. The Trauma and Stroke networks need from the outset to be closely linked in to the Consortium arrangements for referral and assessment, to enable timely transfer of patients to Consortium-funded units. How is this to be addressed?

- Specialist follow-on transitional, community and vocational rehabilitation, which is currently extremely variable across London, and is very much a post-code lottery. This fragmented provision should in particular be addressed by the Joint Committee of PCTs as a matter of urgency.

- Follow-on support in the community should be no less specialised and informed than acute care, to enable brain injured people to maintain and consolidate rehabilitation gains made, and live a meaningful life in the community. What are the plans to review and improve shortfalls in this provision?

We suggest that this whole area - which is essential to building on the initial good outcomes following acute treatment - should be addressed in a co-ordinated and integrated way pan-London by Health & Local Authorities working together, and involving other agencies, such as DWP and the voluntary and private sectors. There should be a thorough review of what currently exists in London - and how well it is working - and of effective services in other parts of the UK and abroad.

The aim should be:

- to ensure equality of access to appropriate and timely services wherever the person lives and whatever their social and cultural background

- to specify what kinds of services need to be in place - including skills and capacity, and service configurations in terms of client groups and populations served (including the need for service networks)

- to clarify and inform commissioning arrangements, so as to facilitate transitions between services.

Without such follow-on rehabilitation and support, the excellent rapid response and acute treatment being planned will be severely compromised, both as regards the long-term cost-effectiveness of the initial response and the quality of life of the survivors and their family and carers.

May 2009