

## Neuroscience Implementation Project Stakeholder Information Document

### ***Purpose of the document***

The purpose of this document is to inform patients, the public and other stakeholders about the changes likely to take place over the next few years in neuroscience services in Scotland. It explains what neuroscience is, the reasons for change and the new model that was proposed in the policy document 'Delivering for Health'. The document aims to explain the ways in which the services are likely to change and what this will mean for patients. It also informs stakeholders on how they can offer their views and opinions.

The views of patients, their carers and the general public are important to consider when services are planning for change. It is also important that people understand how the changes might affect them. This is why we would like to hear your views on what needs to be considered while we are planning for these changes. You should find all the information you need in this document, including how to give us your views on what is important to you.

### ***Background***

In 2004 an Advisory Group, chaired by Professor David Kerr, was set up by the Minister for Health and Community Care. It aimed to look at a range of services within NHSScotland and to develop a National Framework for Service Change, making recommendations for improvements to services. One of these areas was neuroscience. An Action Team was set up to look at the future requirements for this specialist care in Scotland and provide its findings and recommendations to the Advisory Group.

The final report made a number of recommendations for change in the care of people with neurological conditions requiring neurosurgery. In particular, it recommended that we should take a national approach to the provision of services instead of having a number of different services which worked independently of each other. A number of benefits were identified and suggestions were made about how to realise these benefits. Since then, an implementation group has been looking at how to turn these recommendations into practice.

### **What is neuroscience?**

The term 'neuroscience' or 'clinical neuroscience' refers collectively to a group of specialist disciplines. The two major specialties are neurology (medical) and neurosurgery (surgical). Along with a wide range of other specialists, neurologists and neurosurgeons treat people with disorders of the nervous system. These disorders include problems affecting the brain and spinal cord, and the nerves and muscles in the rest of the body. The nervous system is extremely complex and when something goes wrong, specialist advice and care is needed to identify and treat the problem.

### **Who uses neuroscience services?**

Disorders of the nervous system are quite common. Not all are serious and many can be dealt with locally; in primary care and in the community. Some people will need to be referred to a secondary care facility, like a local hospital, and some people requiring more specialist care will need to go to a neuroscience centre. Neurology, the medical branch, deals with all sorts of conditions like multiple sclerosis, Parkinson's disease, motor neurone disease and epilepsy. These are long-term conditions which may be treated or managed with occasional outpatient appointments or may sometimes require hospital admission.

Neurology also provides outpatient diagnosis for people who are referred by their GP or local hospital for investigation of symptoms such as persistent headache.

Some patients will require the specialist intervention of a neurosurgeon. About half of the operations carried out in neurosurgery are classified as 'planned care', and half are classified as 'emergencies'. Neurosurgeons also operate on tumours in the brain and spinal cord, and on people who have degenerative spinal conditions. These are generally not urgent and can be planned in advance. There are also less common procedures, such as surgery for epilepsy or movement disorders, which are suitable for a small number of people. Emergency admissions are usually because of injury to the brain or spine or because of bleeding not caused by injury (like a brain haemorrhage).

Anyone might need these services at some point in their lives, whether locally or at a specialist centre, as a planned admission or as an emergency.

Neurology and neurosurgery also require to have other specialists close by. These include:

- *neuroradiologists*, who provide diagnostic information from scans and also have a major part in treating certain conditions like cerebral aneurysms

- *neuroanaesthetists*, who have the specialist skills needed to take care of neurosurgical patients during their operation and in intensive care
- *neurophysiologists*, who provide important diagnostic information about conditions such as epilepsy and peripheral nerve disease
- *neuro-oncologists*, who specialise in the treatment of tumours in the brain and spinal cord.

People needing neurological or neurosurgical care may, depending on their condition, also require advice or treatment from a very wide range of other professionals such as physiotherapists, speech and language therapists, rehabilitation specialists, psychologists, social workers, community support, and others.

### ***What do service users want?***

The Scottish Neurological Alliance, which is an organisation made up of members from many voluntary organisations representing people with a wide range of neurological conditions, suggested that the sort of issues that matter most to those who use the service are:

- independence and quality of life
- co-ordinated care across different medical contacts
- comprehensive assessment
- user involvement
- established care pathways
- high quality information
- speedy access
- equity of service provision.

Representatives of the Scottish Neurological Alliance were involved in the work of the Action Team. They said that the focus of change should be on patients and not on organisations and structures, aimed at developing services staffed by professionals with wide knowledge of a range of neurological conditions. Their key priority was an integrated Scotland-wide service which should provide equity of access to diagnosis, assessment and treatment, which should be provided as locally as possible. Inter-disciplinary working at all levels and with other agencies, such as voluntary organisations, should be promoted. The Alliance also recognised that some conditions would need to be treated in a specialist centre where treatment could be delivered by the most skilled and experienced professionals.

## **Why change?**

### ***The current service***

Patients with neurological problems may receive treatment from the NHS in a wide variety of settings and often also have help from a range of voluntary, charity and local authority organisations. Research suggests that services vary considerably across Scotland – in other words, people who live in one part of the country may find it easier to get access to the services they need than people in another place. Also, it was found that the providers (the NHS, local authorities, voluntary organisations) do not work together as well as they could in providing services to patients.

Specialist neurosurgical services are currently provided in four centres: Aberdeen, Dundee, Edinburgh and Glasgow. Adult patients are treated in all four sites and children are operated in most often in Glasgow and Edinburgh, and less frequently in Aberdeen. Each of these units forms part of an integrated neuroscience service and is attached to a University medical school.

The units vary in size, facilities and catchment population (the number of people who live in the area served by the unit). The biggest centre is Glasgow, which has a catchment population of around 2.6 million. Edinburgh has around 1.3 million, Aberdeen around 0.75 million and Dundee around 0.6 million.

### ***Drivers for change***

There are also a number of practical reasons why the current service model may not work in the future and why we now have to look at changing it. Broadly, these are;

- Population change
- Availability of skilled staff
- Employment regulations
- Sub-specialisation (specialisation in a particular aspect of neurosurgery)
- Quality of care, standards and clinical governance

### ***Population change (demography)***

Overall, Scotland's population is falling and the profile of the population is ageing, and this is predicted to continue at an accelerating rate for the next 40 years. This has an impact on the provision of healthcare because in general, the older a person is, the more ill-health they will have, and it also means that the workforce available to provide for the increasing demand will be smaller as the birth rate continues to fall.

The pattern of change is not consistent across the country. It is predicted that the biggest falls in the population will be in Orkney and the Western Isles, while Lothian's area is expected to experience population growth. There is also variation between rural and urban areas, with the rural areas expected to have higher proportions of older people. This means that there will be changes in the numbers of people needing neuroscience services, and where they live.

### ***Availability of skilled staff***

Skilled, specialist staff who provide neuroscience services are scarce. This is the case in medical, nursing and other health professions in adult and children's care, and in the other essential specialties such as neuroanaesthetics, neuropathology and neuro critical care, and in technical support services such as neurophysiology. This means that it may become difficult to provide the full range of necessary specialist services in several different places.

### ***Employment regulations***

There are a number of regulations which the Government and NHSScotland must comply with. These include Working Time Regulations, which apply to all staff, junior doctors' training requirements and new contracts for consultants. They are aimed at ensuring that all staff work only a certain number of hours per week and are able to provide a safe service and achieve a work/life balance.

However, the regulations do mean that an increased number of doctors at consultant and training levels are needed to make sure that rotas are compliant. This may be difficult for services which provide for emergencies, as there is a requirement to have staff 'on call' at all times, and also may be difficult for units which only have a few consultants providing a specialist service.

New methods of training doctors are also being introduced. They mean that trainees must have structured training plans which detail the experience they require in order to progress. In specialised services such as neurosurgery, where some procedures happen only rarely, it can take a long time for the trainees to see enough of them to be properly experienced. This is made more difficult by the restrictions on the hours the trainees can work. Having more doctors in training also reduces the chance of each individual doctor seeing the required number of procedures that they need to be fully experienced.

### ***Sub-specialisation***

For some low volume and complex conditions, where a limited number of cases are seen each year, it makes sense for someone with a lot of experience to see all the patients instead of a lot of centres or teams seeing only patients very occasionally. In this way, experience can be built up and patients are treated by the doctor who has the most knowledge about how to treat the condition. This is already the case for some conditions in Scotland – for instance, children with problems in the bones of their skull and face (cranio-facial abnormalities) are all operated on by the surgical team in Glasgow. This kind of approach requires agreement and cooperation among all the health professionals who may see the child. A discipline like neurosurgery has within it a number of procedures which are done infrequently and where strengthening experience and expertise by concentrating the activity could be of benefit to the patients.

### ***Quality and clinical governance***

Some research suggests that there is a measurable link between the number of operations a surgeon and/or team or unit perform, and how well the patient does after surgery. This is called a 'volume-outcome relationship' and the basic premise is that the more of a particular operation a surgeon or surgical unit performs, the better they become at doing it.

This is very difficult to measure in neurosurgery where the numbers of operations are quite small. Some research has been done on individual neurosurgical procedures, but not enough to give general evidence which proves that neurosurgical units, or individual neurosurgeons, have any better results if they perform more of a particular operation.

However, there is evidence of a volume-outcome relationship in other areas and most people would agree that for operations that need done only rarely, it is better if the surgeon, or unit, who does it has a lot of experience. In practice, this means that some surgical procedures which are currently done on four sites might be more appropriately provided in just one.

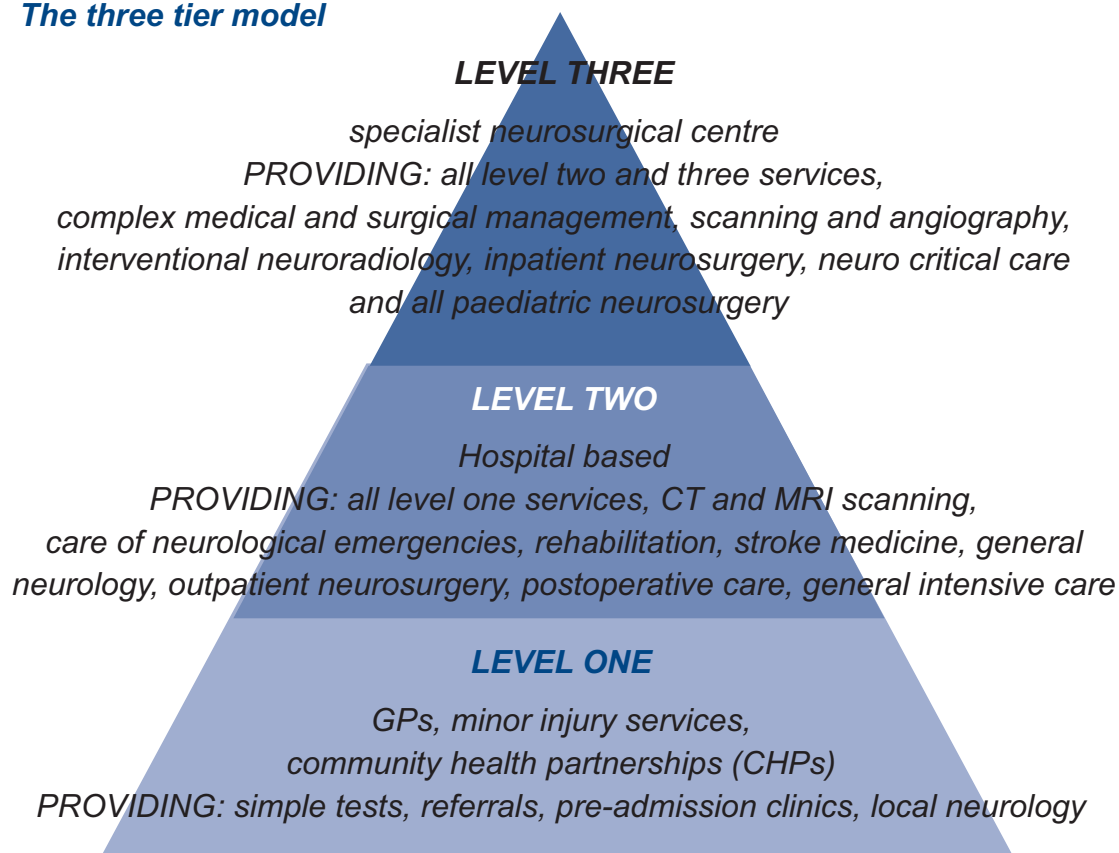
This is particularly applicable to neurosurgery for children which is very low volume. 'Delivering for Health' looked at all the available evidence and made a clear recommendation that because of the small numbers involved, all paediatric neurosurgery should take place on one site, within a highly specialised paediatric hospital with paediatric intensive care facilities, and that it should be located beside an adult neurosurgical centre. None of the existing units meet this standard at present.

### **The new model – proposals**

The recommendation of ‘Delivering for Health’ is that a three tier model of neurosurgical care is adopted, with specialist procedures concentrated on a prime site. This three tier model describes a pyramid of care through which patients would pass, as necessary, from level one (local clinics and neurology, simple tests and referrals, and community based rehabilitation services) through level two (more complex diagnostic tests, outpatient care, pre and post operative and emergency neurosurgical care based mostly in District General Hospitals) and finally on to level three where necessary. Level three, the top of the pyramid, will be a specialist neurosurgical centre, co-located with all the other neuroscience specialties. It will provide complex medical and surgical management, inpatient neurosurgery and all paediatric neurosurgery.

Supporting this model will be improved communication, agreed standards for care, more co-operative and consistent working through and across the many professional groups involved in patient care, and clear guidance on where, how and when patients should be treated.

### **The three tier model**



This will be approached using the principles of Managed Clinical Networks. These are made up of health professionals and organisations from primary, secondary and specialist care, who work together regardless of professional or geographical boundaries to make sure that all patients have access to high quality, effective care. They promote integrated approaches by bringing together all elements of care and by encouraging strong patient and family involvement in the delivery of that care.

### ***The new model – implementation***

What this means is that the most highly specialised adult and children's neurosurgery would be concentrated on a prime site, which would enable the scarce resources, expertise and skills to be accessible to provide the best outcome for patients. As much would be done as locally as possible, both before an operation (tests and other preparation) and after (recovery as an inpatient in local hospital where necessary, long-term care and community based rehabilitation). With this support in place, patients would be able to go home as soon as it was safe and would have to travel only for their specialised surgery or other inpatient management.

The implementation group is considering the practicalities of all these recommendations, in the context of the other workforce and regulatory issues, and focusing on how the existing neurosurgical units could most effectively form part of the Scotland-wide neuroscience service.

In developing detailed proposals for change, the guiding principle has to be what is best for the population in terms of access, quality, safety and expectations. In implementing this new model, we will have to look carefully at transport and travel issues for both patients and carers, capacity and workforce issues, and how to ensure that all patients experience a service which is effective, coordinated and delivered at the right time, in the right place.

### ***Involvement***

We would like to hear your views. You can write to us at:

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email us at: [neuroscience@scotland.gsi.gov.uk](mailto:neuroscience@scotland.gsi.gov.uk)

respond via on-line questionnaire at: [www.scotland.gov.uk/neuroscience](http://www.scotland.gov.uk/neuroscience)

**More information is available at [www.scotland.gov.uk/neuroscience](http://www.scotland.gov.uk/neuroscience)**