West of Scotland Regional Planning Group

The Scottish Epilepsy Centre: Request for Capital Bid

1. Background

Quarriers has been planning over recent years to develop a new Scottish Epilepsy Centre located near to and integrated with the Institute of Neurological Sciences at the Southern General Hospital, Glasgow. A summary of their proposal is attached at Appendix 1. Quarriers have been advised both by the Cabinet secretary and also by potential donors that a capital contribution from NHS Boards will be an essential prerequisite for the development of the new facility. West of Scotland Boards were already in discussions with this organisation in an attempt to regularise the funding agreements and put in place a regional service level agreement to secure equity and improved value for money across the region. This paper summarises the current demand for this service from Boards within Scotland and highlights some of the issues to be considered in decision making.

2. Activity and Costs

Current funding flows into Quarriers from Scottish Boards are laid out below in Table 1.

<table>
<thead>
<tr>
<th>QUARRIERS Scottish Epilepsy Centre Invoicing</th>
<th>Year ending 31 March</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2006</td>
</tr>
<tr>
<td></td>
<td>£</td>
</tr>
<tr>
<td>% share</td>
<td></td>
</tr>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>74,748</td>
</tr>
<tr>
<td>Borders</td>
<td>0.0</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>0.0</td>
</tr>
<tr>
<td>Fife Health Board</td>
<td>65,022</td>
</tr>
<tr>
<td>Forth Valley Health Board</td>
<td>20,279</td>
</tr>
<tr>
<td>Grampian Health Board</td>
<td>81,722</td>
</tr>
<tr>
<td>Greater Glasgow &amp; Clyde</td>
<td>352,853</td>
</tr>
<tr>
<td>Highland Health Board</td>
<td>20,543</td>
</tr>
<tr>
<td>Lanarkshire Health Board</td>
<td>207,000</td>
</tr>
<tr>
<td>Lothian Health Board</td>
<td>0.0</td>
</tr>
<tr>
<td>Orkney NHS</td>
<td>0.0</td>
</tr>
<tr>
<td>Shetland NHS</td>
<td>0.0</td>
</tr>
<tr>
<td>Tayside</td>
<td>0.0</td>
</tr>
<tr>
<td>Western Health &amp; Social Services</td>
<td>0.0</td>
</tr>
</tbody>
</table>

821,757 100.0 907,376 100.0 811,339 100.0 791,075 100.0

NB Info supplied by Quarriers data also being sourced directly from NHS Boards to cross check.

3. Scale of any Capital Contribution

Planning permission for the new Centre has now been granted and Quarriers plan to start construction in 2011 if sufficient funding is secured. The aim is to have the Centre fully functional by 2012. The capital cost of the project is £6.79 million (a full breakdown of costs is available at page 6 of Appendix 1). Quarriers will commit £1.2 million from their own funds leaving a balance of £5.59 million to be funded. They have indicated that they are requesting a minimum contribution of £2 million from West of Scotland Boards on the basis that they will need this to secure matched funding from key donor organisations. An indicative split of this across West of Scotland Boards based on utilisation is as follows:-
**4. Discussions held to date**

Dr Phil Robinson and Hilary Mounfield have held initial discussions with Nicola Sturgeon and have subsequently met with Robert Calderwood and then with Heather Knox and Jonathan Best to discuss this proposal further. In addition to clarifying the scale of the capital contribution, additional information has now also been provided in relation to 2 key areas:

- Further breakdown and explanation of current and proposed revenue costs
- A fee structure, going forward, for Boards who have contributed to the capital costs of the building reflecting this contribution in a reduced rate for the core assessment service

**4.1. Current and proposed revenue**

<table>
<thead>
<tr>
<th>Turnover</th>
<th>£000</th>
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</thead>
<tbody>
<tr>
<td>2005/6</td>
<td>821</td>
</tr>
<tr>
<td>2006/7</td>
<td>907</td>
</tr>
<tr>
<td>2007/8</td>
<td>824</td>
</tr>
<tr>
<td>2008/9</td>
<td>774</td>
</tr>
<tr>
<td>2009/10  (at Aug £484k)</td>
<td>1161</td>
</tr>
<tr>
<td>2010/11  Projection</td>
<td>1147</td>
</tr>
<tr>
<td>2011/12</td>
<td>1213</td>
</tr>
<tr>
<td>2012/13</td>
<td>1279</td>
</tr>
</tbody>
</table>

Quarriers have commented that the turnover projected for 2009/10 reflects the expected level of referrals with a full consultant complement which is now in place. Through discussion they have also made clear that the increased referral pattern is partly based on an assumption of repatriation of Lothian patient flows from England. However, neither Lothian Board nor NSD have funded any patients for treatment in England in recent years so the projected increase in activity is unlikely to be realisable.

**4.2. Revised fee structure**

Quarriers have indicated that the current rate of £2,750 per week will be maintained for those Boards willing to contribute capital; the assessment rate will increase for other Boards to around £3,250 per week. This differential would be maintained for an agreed period and reviewed annually.

**5. Issues for Consideration and next steps**

West of Scotland Boards need to decide in principle whether they are willing to support this development and contribute capital to the scheme.

If a decision is taken to pursue this further then more detailed work on revising both capital and revenue costs will need to take place. A more detailed understanding of referral patterns will also be an essential next step. A
sub group of the RPG should be put in place to take forward this work in partnership with Quarriers with appropriate finance and capital planning input.

6. Recommendation

West of Scotland Boards are asked to consider whether they support this development in principle and whether they will contribute capital.

Heather Knox
Jonathan Best
October 2009
The Scottish Epilepsy Centre

Quarriers is planning to create a Scottish Epilepsy Centre located near to and integrated with the Institute of Neurological Sciences at the Southern General Hospital, Glasgow. Our current service is becoming unsustainable due to its relatively isolated location and the condition of the building.

Key grantmakers have informed us that significant capital funding from NHS is a vital pre-condition for their support. Without their support, our appeal will fail. We are therefore seeking an investment from the West of Scotland Regional Planning Board, not simply to guarantee the continuation of this crucial service, but to create a new world-class service delivering the best possible assessment and diagnosis for people with epilepsy in the West of Scotland.

Quarriers

Quarriers has been supporting people with epilepsy since 1906. Today we provide clinical diagnosis and treatment, supported living, respite and a range of community-based initiatives. These services deliver direct, intensive support for 750 people with epilepsy each year and indirectly reach many thousands more.

Epilepsy

Epilepsy can happen to anyone at any time and can be utterly devastating. It destroys lives and it ends lives. Out of 39,000 Scots who have epilepsy, 26,000 have it controlled through medication. But 13,000 live each day in fear of recurring seizures. These range from brief lapses of awareness to severe seizures with loss of consciousness, significant risk of injury and even sudden death. Epilepsy is more than just a medical condition. Unmanaged, it can destroy every aspect of life – education, employment, relationships and self-worth.

Epilepsy has suffered from historical neglect. People live restricted lives because Scotland does not have the skills or infrastructure to treat them properly.

THE SCALE OF NEED IN THE WEST OF SCOTLAND

- 19,500 people in West of Scotland NHS Board areas have epilepsy.
- 4,500 people in the West of Scotland are estimated to have a misdiagnosis of epilepsy. They are prescribed ineffective and potentially harmful drugs while their true condition is untreated. This costs the NHS £6.8m each year - wasting money and wasting lives.
- 3,900 people in West of Scotland NHS board areas have both learning disability and epilepsy. However, many do not receive appropriate support for their epilepsy and continue to endure harmful seizures that compound their disability.
- Prevalence is considerably higher in areas of multiple deprivation. Recent research in the South West of Glasgow found that the prevalence of epilepsy is 1:41 in areas of multiple deprivation, against a national prevalence of 1:131.
- More Scots died from epilepsy in 2007 than died of Aids, Hepatitis, Meningitis, TB and

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1 Joint Epilepsy Council, Epilepsy prevalence, incidence and other statistics, 2005
Appendix 1

cot death – combined. It is estimated that 42% were preventable.

**QUARRIERS’ RESIDENTIAL ASSESSMENT SERVICE**

There is a significant minority (10%) for whom epilepsy becomes a chronic and disabling condition. People with severe and complex epilepsy experience the most frequent, distressing seizures and are at greatest risk of restricted quality of life. But even complex epilepsy is treatable. The specialist residential diagnosis and treatment available at Quarriers’ Hunter House has established a track record of literally transforming lives. It is the only service of its kind in Scotland.

In terms of actual and planned admissions, the service will have received referrals of 118 residential patients from NHS boards in the West of Scotland – a total of 1,934 bed nights – in 2009. This represents 80% of all referrals.

The service receives referrals of those with complex and intractable epilepsy, and those who may have additional support needs such as learning disability or behavioural issues. It has a particular specialism in complex patients with non-epileptic seizures or those experiencing both epileptic and non-epileptic seizures.

Hunter House fulfils a critical role within the epilepsy services in the West of Scotland. Its unique, holistic approach and the expertise and dedication of staff has established a reputation for excellence amongst medical professionals. Those consultants with the greatest expertise in epilepsy are amongst our most frequent referrers. Patients are referred to Hunter House for:

- Specialist assessment where psychosocial and behavioural issues complicate diagnosis and treatment.
- Clarification when there is diagnostic uncertainty i.e. differentiation between various epileptic syndromes or where psychogenic seizures are suspected.
- Reduction of medication burden or change of treatment in people with intractable epilepsy within a safe setting.

Diagnosis depends on witnessing and recording seizures. Though significant, these seizures can be infrequent. Diagnosis therefore depends on long-term (4–8 weeks) residential assessment, with 24/7 monitoring of seizures. This type of service is unavailable within the NHS.

**The effectiveness of Quarriers’ service**

The aims on admission for patients are generally to clarify the diagnosis of their condition, reduce their medication burden and to improve seizure control.

Though working with a highly complex group of individuals, the service achieved these aims for 91% of all patients last year, and partially achieved aims in the remaining 9%. All patients using the service have experienced positive outcomes in terms of improved quality of life. This high success rate is due to:

- Our capacity to offer long-term (up to 8 weeks) residential assessment within a comfortable and homely environment.
- Quarriers’ holistic approach that takes account of the social, emotional and psychological impact of epilepsy alongside the clinical.
- A multi-disciplinary team providing simultaneous assessment.

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<sup>4</sup> General Register Office for Scotland statistics, 2007

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- Our capacity to monitor throughout weekends speeds up diagnosis where seizures are infrequent. NHS video-telemetry units only monitor 96 hours out of 168.

**Cost efficiency of the service**
The resource is also extremely efficient. We estimate our service costs at less than half the cost of replicating the service in the Southern General – probably considerably less\(^6\). It is half the cost of the NSE service currently operating in England.

In addition, correcting a mis-diagnosis of epilepsy delivers significant savings for NHS in terms of reducing medication, inappropriate use of A&E, ambulances, specialists and access to diagnostic technology such as MRI etc. A study based at the Southern General Hospital, Glasgow, of 260 patients with psychogenic seizures seen between 1999 and 2004 found that 49.7% were regularly using emergency services before the correction of a diagnosis, while only 15.5% were doing so 6-12 months afterward\(^7\).

**A VITAL SERVICE ON BORROWED TIME**
Nevertheless, this has been achieved on borrowed time. The building is no longer adequate in terms of its location, condition or equipment:

- **Location** - The isolated semi-rural setting is too far away from medical and emergency services, so we can’t guarantee 24-hour medical care for patients who may have additional or complex health issues. If we need to alter someone’s medication or withdraw it altogether during their stay, then safety demands that we have emergency medical support close at hand. Without it, the options we can offer people become limited.
- **Building** - We can no longer support a contemporary, first class epilepsy assessment service’ from a 1960s prefab building which is at the end of its useful life. Its structural condition and outdated layout does not meet the latest National Care Standards; it has no outpatient facilities and no room for the development of much needed new services.
- **Diagnostic equipment** – Our EEG/videotelemetry diagnostic equipment is out of date and now requires renewal.

The service urgently needs significant investment. If we cannot update our facilities, this highly regarded service will become sub-optimal and have to close by 2011. This will dramatically increase the cost of specialist residential assessment to West of Scotland NHS boards.

**Alternatives to Quarriers’ service**
The cost of residential assessment for West of Scotland NHS boards is currently **£700,000** each year.

On the basis of current referrals, it would cost West of Scotland boards **£1.3m** to send people to the NSE service in the South of England which has no follow-up (found to be critical in Scotland) and presents significant accessibility difficulties for patients and their families.

\(^6\) Based on a unit cost of £385 per bed day at Hunter House compared with £782 for the Southern General Hospital Neurology Unit. However, once costs for video telemetry monitoring, neuropsychology, neurophysiology etc. are added, the true cost is likely to be considerably higher.

\(^7\) McKenzie et al. Early outcomes and predictors in 260 patients with psychogenic non-epileptic attacks (PNEA). Neurology, in press.
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To provide the service in Scotland – within an NHS neurology setting – would cost West of Scotland boards an estimated £1.4m merely to admit patients. But once costs for video-telemetry monitoring, neuropsychology, neurophysiology etc. are added, the true cost would be considerably higher. However:

- It would be very difficult for the NHS to accommodate patients in acute beds for 4-8 weeks. This means providing an additional 2,000 bed nights per year which would jeopardise the achievement of waiting list targets.
- NHS video-telemetry units do not monitor 24/7 meaning that many seizures would be missed, prolonging admission times.
- 50% of patients referred to Quarriers have additional complex needs including learning disabilities and behavioural issues. Hospitals are simply not designed to support these groups.

OPTIONS
An options appraisal considered various alternatives for the future provision of specialist residential assessment and diagnosis of Epilepsy in Scotland.

- A refurbishment of the existing building would, while costly, reduce overall occupancy from ten beds to seven beds, increasing waiting lists.
- A complete rebuild on the site of Hunter House would greatly improve the building situation but would not address the more serious issues in terms of 24hr neurology cover and proximity to emergency services.
- If the service was allowed to close, a group of people with very complex needs would have nowhere to go. They will have to endure frequent, violent and potentially fatal seizures with a devastating impact on their lives.

Quarriers has therefore decided to take a comprehensive approach and radically reshape the service. This will deliver improved, more accessible and cost-effective treatment for people with the most severe epilepsy.

THE SCALE OF OUR VISION
In consultation with partners and patients, we have conceived a bold, ambitious, yet achievable vision – we will develop a truly world class epilepsy service.

We will achieve this by developing a purpose-built Scottish Epilepsy Centre, located near to, and fully integrated with the Institute of Neurological Sciences at Glasgow’s Southern General Hospital. This will combine Quarriers specialist expertise with one of the world’s finest neurology teams allowing access to emerging clinical practice and provide the opportunity to share learning. It will also enable access to their MRI, CT scanners and other diagnostic technology.

This partnership is the key to realising our ambitious vision. It will facilitate the creation of a national centre of excellence providing a service comparable with the very best in the world. The new facilities will also give the capacity to significantly enhance existing therapeutic and advisory services, introduce new ones such as telemedicine and develop research and training programmes.

Through accurate diagnosis and treatment, the Scottish Epilepsy Centre will transform the lives of 200 people with the most complex epilepsy each year and, through training, research and outreach work, support many thousands more. It will be a world-class resource of which Scotland can be proud.

A BUILDING DESIGNED TO TRANSFORM LIVES
The Scottish Epilepsy Centre has been designed by Anderson Bell & Christie. We consulted with a range of people who currently use Hunter House and their views
significantly influenced the building design, focusing on location, building style, environmental issues and also the structure of the service.

The building will have 12 residential assessment beds which can all provide comprehensive EEG video monitoring. It will provide consultation rooms for outpatients, psychology facilities, a research resource, telemedicine suite and a large conference room.

Located very close to Glasgow’s Southern General Hospital, it will enhance the quality of service and outcomes delivered for patients in the following ways:

**More accurate and quicker diagnosis**
As diagnosis depends on seizures being witnessed and recorded, the building has been designed to maximise observation. With the latest EEG video monitoring equipment, we will be able to observe and record seizures occurring in any part of the building – significantly increasing the likelihood of visually recording a seizure. These features will maximise successful diagnoses and make them quicker, perhaps by 25%. This will enable us to reduce admission time – making the service considerably more cost-effective while increasing capacity.

**Proximity to the Southern General Hospital**
The service will benefit greatly from being located closer to other related medical services such as accident and emergency services, pharmacology, brain imaging and surgical facilities. Critically, this will also establish robust medical and technical cover, resolving the difficulties of supporting people with additional health needs and responding to emergencies. Access to wider professional networks will increase multi-disciplinary input.

**A safe and supportive environment**
Combining hi-tech diagnostic facilities with a homely environment, the centre will allow patients to live comfortably during their assessment, which for some can take up to 8 weeks, alongside the best clinical support.

All areas accessed by patients are on one floor to maximise observation and take into account the risks associated with epilepsy. Accommodation will be age appropriate and accessible for people with disabilities. Two sleepover rooms for relatives are included. Patients have highlighted the importance of parents and families in supporting them to come to terms with the devastating diagnosis of a serious and long-term condition - and learning to live with and manage it.

**Developing new services**
The new resource will enable the development of much needed new services:

- Establishing improved outpatient services and effective pre-admission and post-discharge support.
- Developing day care assessment for patients with additional needs, particularly learning disability – making the service more accessible for this group.
- Telemedicine with video-telemetry facilities will enable our specialists to hold long-distance consultations with patients and their doctors.
- Expanding our Epilepsy Specialist Nurse and Fieldwork outreach services.
Neurosurgery
The new centre could also play an important role in the development of an epilepsy surgery programme in tandem with the Southern General Hospital. The epilepsy centre could identify candidates for surgery and provide pre and post-operative care, freeing up acute hospital beds.

Developing Research
Epilepsy is a poorly understood condition. The new building will include facilities for much needed research. This would include issues such as the management of patients with complex needs and non-epileptic seizures. Knowledge gained would enable us to make huge steps forward in understanding the illness and improving treatment and practice.

A National Focus for Epilepsy
The Scottish Epilepsy Centre will become the natural focus for epilepsy for health and social care professionals. The best practice developed at the centre will help raise expectations and standards of care for everyone with epilepsy.

We will also provide placements for three Neurological trainees each year as part of their training. This will increase the number of Neurologists in Scotland with an understanding of the condition and increase the likelihood of some choosing to specialise in epilepsy. The unit is a valuable source of teaching material on epilepsy for neurological juniors as well as trainees in other specialties such as psychiatry and learning disability. Due to its current location, the teaching of neurological juniors is limited. Once it is close to the Southern General, there will be more opportunities for junior doctors to be involved with the service and will be able to learn from the unique experience available there.

Through existing links with the University of Glasgow and Caledonian University, we will develop course modules for nursing and medical students and offer student placements. We will aim to expand training to include GPs and other healthcare professionals. This will increase their knowledge of this complex condition, resulting in better diagnoses and more timely referrals for appropriate specialist treatment.

DELIVERING THE SCOTTISH EPILEPSY CENTRE
Scotland needs this resource urgently. Following consideration of nearly 20 different sites, an excellent site became available. It is very close to the Southern General Hospital and meets all our criteria perfectly. We have now committed to this site and this means we need to deliver the Scottish Epilepsy Centre by 2012. Planning permission has been granted. We are aiming to commence building in 2011, subject to funding. The building will take 14 months to complete and will be fully operational in 2012. We have costed these ambitious plans to create a world leading service at £6.79m.

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>Fundraising begins</td>
</tr>
<tr>
<td>2010</td>
<td>Site becomes available</td>
</tr>
<tr>
<td>2011</td>
<td>Tender</td>
</tr>
<tr>
<td>2012</td>
<td>Building commences</td>
</tr>
<tr>
<td></td>
<td>Building complete and operational</td>
</tr>
</tbody>
</table>

Cost breakdown
- Building £4,810,000
- Land £270,000
- Demolition £130,000
- Prof. Fees £540,000
- Additional fees £70,000
- Contingency £500,000
- Equipment £470,000
- Total £6,790,000

Capital Funding Sources
The initiative represents one of the most important developments in the history of epilepsy treatment in Scotland. The sheer scale of need demands all the focus,
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energy and resources that Quarriers is able to give. Quarriers will contribute £1.2m from our own resources – a significant commitment for a charity that does not maintain large cash reserves.

We have developed and implemented a classic capital campaign fundraising strategy. A Leadership Council of prominent Scots is being recruited to drive the Appeal. We are currently engaging with a number of grantmakers, companies and philanthropists.

**Ongoing Revenue Funding**
The service will be costed on a break even basis with any surpluses reinvested in the service. It will cost £1.166m to run in the first year of operation and we anticipate income of £1.169m in year 1. These forecasts are based on an occupancy rate of 75%. The service is currently achieving an occupancy of 80%. Funding arrangements are already in place with our existing referral partners. Currently NHS Boards fund the service on the basis of individual referral contracts for in-patient and out-patient activity.

**Staff Structure**
The centre will be comprehensively staffed. The clinical team will be contracted from the Institute of Neurological Sciences comprising two Consultant Neurologists, a Consultant Neurophysiologist, a Clinical Neurophysiologist and a Clinical Neuropsychologist. A Centre Manager will have overall operational responsibility for the service, including nursing and support staff team, Assistant Psychologist and Epilepsy Specialist nurses.

**Ensuring outcomes are delivered & quality is consistent**
Quarriers will register the unit as an Independent Healthcare Establishment with the Scottish Care Commission for the Regulation of Care. This will provide a robust external validation and monitoring process in line with the Scottish National Care Standards. Primarily, we will review the aims on admission for each patient against achievement on a quarterly basis. We will actively involve patients in the monitoring and evaluation process. The existing service is committed to excellence and was the first independent hospital in Scotland to achieve the European Foundation for Quality Management award. This model of quality management measures all aspects of the service and is externally validated by Quality Scotland.

**PARTNERSHIP WITH WEST OF SCOTLAND NHS BOARDS**
Nicola Sturgeon, the Scottish Cabinet Secretary for Health and the Health Department are extremely supportive of our proposals. However, she has advised us that the Scottish Government does not have the power to award capital grants to bodies other than NHS organisations.

Key foundations and philanthropists have also expressed strong interest. However, due to the clinical nature of the service and issues of additionality to NHS responsibility, they have informed us that their support is entirely contingent upon first securing significant capital funding from the NHS. Without substantial statutory input, we will lose the support of our key charitable donors and our appeal for capital funding will fail. Consequently, Quarriers would no longer be in a position to continue offering this service.

We are therefore seeking a significant investment from the West of Scotland Regional Planning Group. This will not simply guarantee the continuation of this crucial service, it will lead to the delivery of world-class assessment and diagnosis for people with epilepsy in the West of Scotland. The investment will
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leverage millions in grants from private donors, realise considerable ongoing savings for West of Scotland NHS boards over the cost of providing a more expensive alternative service and deliver positive outcomes for patients.