Lothian Neurological Care Improvement Plan
2014 to 2017
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1. Introduction

In Lothian, it is estimated that there are 53,480 people living with a neurological condition, of whom 5,348 will be disabled by the condition and 1,872 will require help with all the tasks of daily living. Around 8489 people in Lothian will receive a new diagnosis of a neurological condition each year. Having a neurological condition is the most likely reason for experiencing complex and physical disability for people aged under 65.

Neurological conditions include epilepsy, seizures, chronic headache and migraine, Parkinson’s disease, multiple sclerosis, acquired brain injury, Huntington’s disease, dystonia, functional neurological symptoms, cerebral palsy, motor neurone disease, muscular dystrophy. Common neurological symptoms include dizziness, seizures, paralysis, headache and sensory symptoms. Neurological problems can be acquired as a result of injury (primarily brain injury) arising from trauma or as a consequence of necessary surgical intervention.

It has been estimated that around 17% of GP consultations (in Lothian this equates to 918,000 GP consultations per year) and 10% of emergency department visits (for Lothian 22, 900 emergency department visits per year at a cost of £30M, based on a unit cost of £131 per visit) are for neurological symptoms. There are around 24,000 neurology outpatient appointments per year (£1.7M) and around half of new referrals are for headache, functional symptoms and epilepsy.

When we looked at data within the Integrated Resource Framework for a small cohort of people under the age of 65 that we could identify as having a diagnosis of a neurological condition (circa 1,880) we found that in one year this group of people had attributable total resource utilisation across NHS and social care of £50,328,784.

Even for one of the most common long term neurological conditions, Parkinson’s Disease, on average a GP will encounter a person with a new diagnosis of Parkinson’s only once every two years.

Around 15-20% of medical unit admissions and 40% of inpatients on medical wards have neurological problems that could benefit from neurological or neurosurgical care.

As has been the case across the UK, national leadership on neurological conditions has been as a response to recognition that people with on-going neurological conditions are the “missing millions” experiencing disadvantages of complex disability at a young age with fragmented and inconsistent service.

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provision across the public sector as a whole and within health and social care systems.

In Scotland, Healthcare Improvement Scotland (HIS) began a programme of review and improvement in 2005\(^2\). It’s helpful to note the major issues emerging from the HIS review of services which formed the drivers for the commencement of the improvement programme.

The review of neurological services identified that NHS boards appeared to consider neurological health services a low priority:

- NHS boards were unable to describe their neurological services accurately
- there was limited partnership working with neurological voluntary organisations, and
- there was a lack of awareness of the impact of functional neurological symptoms which led to inconsistent care.

HIS developed standards “Neurological Health Services – Clinical Standards 2009” and initiated a cycle of improvement with NHS boards. Lothian had been participating in this Improvement work, focussing on delivering the standards. One of the standards required of NHS boards is that they have a three-year plan for the development of neurological care.

In 2012, NHS Lothian began work on developing its plan for neurological care. The plan takes a broader perspective, in line with NHS Lothian’s strategic framework “Our Health, Our Care, Our Future: NHS Lothian Strategic Plan 2014 – 2024”. Whilst this plan incorporates the delivery of the standards, its purpose and hopefully its strength is to focus on patient need and service excellence, join up our assets as a means of managing pressures and delivering performance targets across the system as a whole.

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\(^2\) Health Care Improvement Scotland, Neurological Health Services in Scotland Final Report 2012
I) Figure A – Overview of services

The red triangles are an attempt to indicate some of the points of patient administration.
1.1 Introduction to services for people with a neurological symptom or condition in Lothian

In Lothian, neurology and neurosurgery (in-patient, out-patient and day case) are provided by the Department of Clinical Neurosciences which also provides care across south east Scotland. Neurosurgery is one such regional service.

Specialist neuro-rehabilitation services are provided by the directorate of rehabilitation medicine, currently based at the Astley Ainslie Hospital (AAH) and managed by Edinburgh Community Health Partnership (CHP). These include an in-patient unit for people with progressive neurological conditions, national in-patient units for patients with brain injury and patients with brain injury who also experience mental health problems (Ferguson Unit at the Royal Edinburgh Hospital). Rehabilitation medicine also provides in-patient rehabilitation for people who have had a stroke, amputations or experienced trauma. A range of out-patient rehabilitation services are provided, including programmes for the management of ME-CFS, cardiac rehabilitation and chronic pain management.

Services for people with Parkinson’s disease are provided by Medicine of the Elderly, though with some specialist therapies provided by rehabilitation services at the AAH, supplemented with input from Neurology and from psychiatry.

The Department of Clinical Genetics currently has a key role in care of people with Huntington’s by virtue of its role in familial screening.

Neurology, Huntington’s specialists and Parkinson’s services provide support across Lothian’s acute sites, Royal Infirmary, Western General, the Royal Hospital for Sick Children and St John’s and to the emergency department in respect of patients admitted to other areas who may have a neurological condition. Each of these areas has plans to strengthen this function as part of their improvement plans.

West Lothian CHP has a local multidisciplinary rehabilitation team for people with neurological conditions (CRABIS – originally for people with acquired brain injury – Community Rehabilitation Acquire Brain Injury Service). Over time the team has developed its expertise and extended its remit. It is a key part of a multiagency network of services in West Lothian for people with physical disability.

There are nurse and care adviser specialists for some on-going neurological conditions: epilepsy, Huntington’s, Parkinson’s, subarachnoid haemorrhage, motor neurone disease and multiple sclerosis. These staff provide high level of expertise, continuity of care and a bridge between primary (community and social care) and secondary care, case management/integration of care for patients.
In primary and community care sectors, people with neurological conditions will access their GPs, district nursing and generic therapy and social care services. However, it is perhaps worth noting that only epilepsy has featured as a long term condition within the GMS Quality and Outcomes Framework for general practices.

2. How we developed the plan

The process of developing the plan has involved the following:

- Stakeholder conference and workshop to identify key themes
- Working with Neurological Voices
- Developing a vision for care improvement
- Developing a vision for the work of the Neurological Care Improvement group and working towards this
- Seeking to build on our assets and joining up for clinical care, planning development

More information about these aspects of the work are given below, but it is worth noting here some of the different perspectives and priorities that have shaped the current plan. In particular, the plan contains two visions.

The first, a vision for the work of the Neurological Care Improvement Group was developed to guide the planning. This was supported by the Neurological Voices but they were very clear that this was a vision for a way of working, not a vision for the improvement of care.

The vision for neurological care which is presented in this document has emerged over the course of the work.

2.1 Stakeholder conference and workshop to identify key themes

Our starting point for developing the plan was an initial conference, with workshops, held in December 2012. Some key issues emerged in the planning of this workshop, most notably, that major areas of development and improvement such as the planning for the re-provision of the Department of Clinical Neurosciences, the planning for a redesign of neuro-rehabilitation being sponsored by the Lothian Physical and Complex Disability Strategy Board, Demand and Capacity Work and work on achievement of the HIS standards were not joined up. For example there was no readily available information on the epidemiology or overall profile of service activity of people with neurological condition.

An initial survey of NHS services for neurological care (Figure A – Overview of Services, page 7) gives an initial indication of the complexity of service provision. Work done subsequently, looking in more detail at services and management arrangements, Figure B, page 11, shows how complex the network is, bearing in mind that even this diagram only shows part of the
picture for a singular neurological condition, services supporting patients with Parkinson's disease. The positions highlighted in yellow are services and in many cases these amount to an individual or very small team. The positions in orange are the managers and their subsequent line management within the overall organisation.
The conference was attended by 68 people from across NHS Lothian, local authorities, the voluntary sector and representatives from the Neurological Voices programme for people living with neurological conditions and their carers.

A lead nurse specialist observed that this conference was the first time in 20 years that everyone involved in care of people had been together in a room, although, as the conference presentations illustrated, substantial developments are underway.

The conference used three strategic aims from NHS Lothian Strategic Clinical Framework as a basis for the workshop discussions.

These were:

- Innovation and research in the development of person centred cost effective care for people with neurological conditions
- Developing joined up working with patients, carers and the voluntary sector
- Involving patients and informal carers as partners

Some of the key themes emerging from the conference have remained a focus of this plan and are fundamental to improvement, most notably

- The need to join up care around patients and carers

And related to this:

- The importance of integrated pathways of care in achieving joined up care (particularly given the complex configuration of services) - though perhaps the issue here is a need to reconfigure services to deliver the pathways
- The need to use technology effectively to do this, particularly in relation to clinical information and shared patient records and the ability to identify people with an on-going neurological condition for purposes of planning and clinical care
- The need to use information technology to improve access, communication and deliver different relationship between professionals and with patients and carers – for example, to provide instant reassurance by telephone, e-mail or video links, an issue which applies to both professional to professional as well as patient/carer to professional communication.
2.2 Working with Neurological Voices

At a national level the Scottish Government has established a National Neurological Advisory Group to maintain the momentum in the development of neurological care. The arrangements to support this include the Neurological Alliance of Scotland and a Neurological Voices Programme to support people with neurological conditions who have taken part in the neurological voices programme. A group of people from Lothian participated in this programme and have continued to meet as Lothian Neurological Voices.

Lothian Neurological Voices Group are represented on the Lothian Neurological Care Improvement Group respectively have been directly involved in the national programme of work. Some members of Lothian Neurological Voices are also involved in voluntary sector groups and in other local planning processes.

The role and remit for the Lothian Neurological Voices Group is included in Appendix 1 and has been endorsed by NHS Lothian Strategic Planning Group.

Lothian Neurological Voices Group undertook an exercise to develop its priorities. The basis for the exercise was the list of themes emerging from the December 2012 workshop.

The top five neurological care development priorities identified by the group are as follows:

1. Development of specialist nurse/neuro-rehabilitation nurses as a bridge between hospital and community
2. Importance of clear pathways
3. Rapid access to service/when needed
4. Care needs to be patient focused
5. Training for caregivers

A regional patient group, the Neurosurgical Voices Group, covering the South East Scotland Managed Services Network for Neurosurgery has also been established.
2.3 NHS Lothian’s Vision for neurological care

Excellence will come from us all (including patients) working together with a common purpose; challenging what we do now in order to develop a more effective service.

1. Provide excellent services and excellent care:
   - Access to services for people with neurological conditions will be clear, structured and easily available to everyone with a neurological condition
   - There will be clear, understandable and integrated pathways of care with clear leadership for as many neurological conditions as possible
   - Services will be provided by multi-disciplinary teams structured and supported to focus on patient's needs with shared patient information, shared care plans and joined up communication
   - All team members will have specialist training in neurological care and there will be specialist services for specific conditions
   - Excellent care means:
     - high quality in all aspects of service provision from administration to clinical communication.
     - joint, fully informed, decision making with the patient at the centre of the process
     - the value of social and emotional aspects of care provision are explicitly acknowledged
   - Learning from a patient’s experience is fundamental to the way that services operate
   - Relationships amongst professionals, patients, families, carers and the public are based on mutual respect and understanding.

2. Deliver excellent training to staff, carers and patients and families.

3. Actively support and engage in research and development to find a cure and improve quality of life for people living with neurological conditions.
The vision for care presented above emerged over the course of the work. This vision is simply expressed and potentially will be seen as ordinary. It would be a stretch to call the wording of this vision transformational or radical, and it is easy to wonder why it wasn’t articulated at the outset. The important points here are that the detail of the planning process has challenged assumptions of what we think is in place. The simple request from Neurological Voices to describe the range of services available and how to access them in a way that is understandable remains a continuing challenge.

Noted below is some of the learning identified along the way – articulated by various members of the neurological care improvement and neurological voices groups:

- We need to design services and pathways of care before we talk about redesign
- We may say we’re doing something, but it’s not necessarily happening
- If we think we are already doing something, we need to demonstrate this and then we need to do more and do it better
- I’m surprised that (in relation to one long term neurological condition) people in the NHS have to go to a conference to hear about what other NHS services do
- It’s hard to believe that we’re proposing that multidisciplinary team working is an innovation
- There seem to be more managers than there are clinical staff
- Not having information to hand is the biggest handicap
- We’re a small fish and senior managers have lots of other fish to fry.

Simple as the vision may appear, underlying it is a challenge to what we think we already know and think we already do. Some aspects of the vision may challenge our assumptions about what we can afford to do in future, other aspects of the vision, like some apparently simple and fundamental actions in the plan for improvement, will be particularly hard to achieve and implement.
2.4 Developing a vision for the work of the Neurological Care Improvement Group

The following collective vision was developed from discussions with members of the neurological care improvement group and wider stakeholders.

There is a picture of people for whom we are providing care that is as clear as possible

There is a clear as possible picture of people who need or would benefit from neurological care

There are full, integrated care pathways for as many conditions as possible

There is a picture of people who do not fit into the care pathways we develop and of our response/how to help

There is a clear statement of the resources we are currently using to provide neurological care

There is a list of interventions that we currently provide and a list that we aspire to provide or are on the horizon

There are established ways of working which support strategic development as well as service delivery and improvement

Neurological services in Lothian have a clear identity which recognises and values the multiple disciplines and specialties which contribute to this, which staff feel part of and which patients feel they are part of also

There is a shared infrastructure to support this neurological service

There is a clear picture of and understanding of the technology and systems currently supporting services

Resources and capacity are used efficiently

We proactively recognise that good care is about all aspects of service provision from administration to clinical communication

The value of intangible aspects of care provision is explicitly acknowledged

Learning from patient’s experiences is part of the way that services operate

The outcomes for patients are articulated and measured (where possible)

Some significant changes to the way resources are currently used to improve care and cost effectiveness of care

There will be a vision for research and development and the relationship with the University of Edinburgh which reflects our service aspirations and vice versa.
This vision indicates some clear areas of work to be undertaken in the planning process. It provides a framework against which to assess the progress of the process and of the working of the Neurological Care Improvement Group and Appendix 2 of this report gives a subjective summary of progress against each of these.

Underlying several aspects of this vision is the aspiration to integrate quality improvement into operational priorities and challenges (efficiency and cost effectiveness, capacity and demand management) and clinical practice in order to deliver strategic change.

- There are established ways of working which support strategic development as well as service delivery and improvement
- We all manage to find time to be proactive rather than fire fighting
- We work together to understand and address immediate service pressures
- We are able to have challenging discussions about how current resources might be used differently to improve care and meet needs
- Resources and capacity are used efficiently.

Three aspects of this vision form important background information for the plan:

1. There is a picture of people for whom we are providing care that is as clear as possible.

**Ways of working**

We are able to have challenging discussions about how current resources might be used differently to improve care and meet needs

We find ways to communicate and work together that are as productive and effortless as possible

We all manage to find time to be proactive rather than fire fighting

We have some good arguments

We recognise and challenge usual assumptions and terminology

We work together to understand and address immediate service pressures

We will build a joint management team for neurological care
2. There is a clear as possible picture of people who need or would benefit from neurological care

3. There is a clear statement of the resources we are currently using to provide neurological care

Further information on each of these is provided in Appendix 3 Who we are looking after and Appendix 4 Statement of resources used to provide neurological care.

The development of full, integrated care pathways for as many conditions as possible forms a major section of the plan and more details on this approach and the development of a **generic integrated pathway of care** is provided in section 3.2 below.

Table 1 below shows the prevalence of conditions for condition specific pathways reviewed or under consideration to date. Figures in bold are those based on data held in Lothian. More details on these figures are included in Appendix 3.

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<tr>
<th>Table 1</th>
<th>Prevalence/ incidence of Neurological conditions in Lothian</th>
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<tr>
<td>Neurological symptom/condition</td>
<td>Lothian prevalence</td>
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<tr>
<td>All headaches</td>
<td>127,334</td>
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<td>Cluster headache</td>
<td>849</td>
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<td>Chronic migraine/tension type headache</td>
<td>42,445</td>
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<td>Epilepsy</td>
<td>5,924</td>
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<td>Refractory epilepsy</td>
<td>1,184-1,777</td>
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<td>Functional neurological symptoms</td>
<td>622-1,222</td>
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<td>All of the above</td>
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Progressive Neurological Conditions

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<td>Parkinson’s</td>
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<td>Motor Neurone Disease</td>
<td>105</td>
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<td>Huntington’s Disease</td>
<td>2,500</td>
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<td>ME/CFS</td>
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Need to note that those below need to be progressed

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<td>Subarachnoid Haemorrhage</td>
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<td>Head injury</td>
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<tr>
<td>Brain injury (long term problems)</td>
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<tr>
<td>Dystonia</td>
<td>552</td>
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<tr>
<td>Cerebral Palsy</td>
<td>1,579</td>
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An illustrative representation of the numbers of the population affected by neurological conditions is provided overleaf at Figure C.

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3 1 Admissions to DCN in 2013-2014 137-ongoing caseload 700

4 3 year prevalence
2.5 Building on our assets and joining up for planning and development

It can be a natural tendency of planning processes to identify gaps and deficits. Whilst this planning process has identified some gaps and much development to be done, we wanted to explicitly identify some assets. Ideally to recognise the importance of asset based development approaches which build on these, but at least to ensure that we don’t inadvertently damage our assets in the planning and development processes.

- The stakeholder conference identified key role of specialist nurses, care specialists and therapists in joining up and co-ordinating care.

- Condition-specific voluntary sector organisations have a key role in lobbying advocating, building skills and expertise research funding and service delivery: (we) “have the focus and we have the energy”.

- University of Edinburgh is a centre of excellence for neurological research for the development of clinical care and services.

- Lothian Parkinson’s Steering Group already in place.

- CRABIS – the Community Rehabilitation and Brain Injury Service in West Lothian is consistently viewed as an excellent, flexible and expert service by clinical staff across the spectrum of care.

Informed by the initial conference, the following adjustments to the planning structures and groups were made in order to integrate developments across neurological care services during the development of this improvement plan:

- The membership of the neurological care improvement group was reviewed to broaden representation across disciplines and across sectors. Membership of the group is provided at Appendix 5.

- The role and remit of the Physical and Complex Disability Strategy Board was also reviewed. This led to the incorporation of Neurological Care Improvement as a whole within its remit. The Neurological Care Improvement Group reports to the Physical and Complex Disability Strategy Board which in turn reports to the Strategic Planning Committee.

- The Neurological Care Improvement Group work and this plan include developments and improvements in pathways of care offered and those required by the planned move to the new Department of Clinical Neurosciences in 2017.

- With the conclusion of this Improvement Plan the NCI Group was disbanded. The work of taking forward the implementation of the recommendations and learning provided by the improvement plan is being taken forward by the Neurological Improvement Leadership Group. Membership of which is provided in Appendix 9.
3. Neurological Care Improvement Plan

3.1 Overview

Earlier sections of this plan have described the network of management and delivery units which provide care for people with neurological conditions. We have also described the importance of joining up care to focus on patients and having clear pathways of care. The structure of this plan is based on a matrix to represent both these approaches—setting out developments that are needed in each of the service units or sectors of the system as well as setting out developments that are needed to build an integrated pathway of care for specific conditions. The figure on the next page shows the structure of the action plan at a glance.

For some of the actions in the plan, and for some of the development areas there is inevitable overlap between the management units, the sectors, cross cutting themes and functions and the development of integrated care pathways for conditions and this means there may be some repetition or duplication. The plan is presented in this way to emphasise the spread of responsibilities for action as well as seeking to ensure that it’s possible to see the specific actions and the groups of patients (pathways) within a bigger picture.

3.2 Development and use of the generic integrated care pathway

Section 2.4 above refers to the development and use of a generic integrated care pathway, provided at Appendix 6. This generic integrated care pathway simply lists the known good practice elements and local tools (such as RefHelp) to support effective demand and capacity management and integrated patient care. The aim in producing this was to be as comprehensive as possible. We prioritised a list of neurological conditions and used the generic integrated care pathway as a checklist for a rapid review of current provision. The following points should be noted:

- The needs of people with different conditions are different, so not all aspects of the generic tool apply in the same way to each neurological condition
- This approach allowed us to identify clearly whether some basic elements of an integrated care pathway were in place or not
- Overall we found that some aspects of the generic integrated care pathway were in place, but that for most conditions integrated pathways had not been developed and were not in place, meaning that individual clinicians and patients were constantly forging their way through systems to access care, albeit with a direction in mind.

Some parts of pathways had been trodden down thanks to “natural leadership” and “natural networks” of clinicians and professionals
### Part 1: Service sector developments

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### Part 2: Generic/cross cutting developments

#### 2.1 Involving patients and carers

#### 2.2 Workforce development plans

Nursing
Pharmacy
Medical
Administration
Psychology
Speech and language therapy, physiotherapy and OT
Social care

#### 2.3 Research and innovation

#### 2.4 Organisational development

Joint quality improvement team
Process consistency eg clinic templates, admin
Joint management Team for Neurology and Neurorehabilitation (DCN and Rehab Medicine)
Development of clinical communications – telephone consultation and advice
Pathway and performance monitoring
E-health
Networks of excellence
Choice and partnership
Conversely there was no planned/supported approach to leading, monitoring and developing pathways as a whole

- The actions we have identified for each of the pathways are those prioritised from the rapid review using the generic integrated care pathway. We have not included a full assessment of progress against all aspects of the integrated care pathway.

3.3 Resource implications

This plan has identified the scale, patterns of use and distribution of resources across the system. It is clear that there are some plausible opportunities for resource/capacity shifts and for the achievement of a more joined up picture of demand and capacity.

At present the following areas of concern should be noted.

- The implementation of the care pathway for functional symptoms (2 wte workers)
- Limited provision of psychology
- Medication is a major area of risk, opportunity and cost, but dedicated clinical pharmacy time is limited and there is no pharmaceutical overview at patient level or at service level across the sectors
- Capacity and coordination of Neuro-rehabilitation AHPs, particularly neurophysiotherapy
- Business cases and staffing models for REH and the new DCN
- Capacity within the organisation for clinical leadership and change
- Opportunity for development of specialist nurse role in relation to headache and introduction of new intervention for complex headache

3.4 High level themes and issues

Chapter 2 of this plan describes each element of the plan in terms of why the topic or issue is included and what we need to do in each of the sectors, in relation to both cross cutting functions (workforce and organisational development) and pathways of care for specific, strategically important, conditions.

The plan as a whole raises some high level issues and it is perhaps worth highlighting these explicitly, lest the wood gets missed as people find their way through the detail of the trees.

Firstly, the current arrangements for services are complex, for a now relatively well defined population of patients with a relatively high level of similar needs.
This makes planning and development complex, as well as requiring considerable effort to provide joined up, multidisciplinary care. One of the consequences of this is that we don’t know some fundamental information about our activity, outcomes for patients and efficiency or gaps in services.

A focus on patient/population centred design of multidisciplinary and excellent services based on designed pathways must lead us to consider the appropriateness of the current organisational arrangements for the management and delivery of services.

Some of the actions in the plan, seeking to build shared patient records, single point of contact (for neuro-physiotherapy for example) are steps towards putting in place an infrastructure for co-ordination. These include recognition that:

- There is a challenge to ensure that pathways are fully integrated across all tiers of health care/social care and the voluntary sector, and that these elements are in place consistently and meaningfully with active evaluation, review and improvement.
- Clear designated clinical leadership of each of these pathways is required.
- A neurological care e-health strategy which supports effective use of existing systems for clinical co-ordination and for engagement with patients is required to maximise efficiency and care co-ordination, and to support the transition to DCN. This needs to include development and use of existing systems, stronger vision and delivery in relation to information sharing (between agencies and with patients) and development of an integrated website.

There are of course network models that offer a different approach to supporting co-ordination and improvement of specialist multidisciplinary care in general. ParkinsonsNet.info is a model that could be used for the different pathways and conditions.

The development of a managed clinical network could perhaps be seen as an approach to “join up” across management units, with similar functions to Parkinsonsnet and the potential for additional co-ordination. However, neither of these approaches directly supports multidisciplinary team working at the interface with individual patients and their families. Arguably, these approaches require an additional organisational mechanism or layer and manage the “symptoms” rather than addressing the underlying complexity.

Overall it seems likely that improvements in neurological care and the delivery of excellence will require a balanced combination of more joined up organisational arrangements and multidisciplinary teams as well as the development of networking functions.
Lothian Neurological Care Improvement Plan 2014 to 2017

Part Two
Service sector developments

2.1 Department of Clinical Neurosciences (DCN)

a) Recording Diagnoses

Ensure that when a diagnosis of a key condition is confirmed by a consultant that the diagnosis is recorded as a diagnosis on TRAK (in the diagnosis field) in the electronic recording system.

We know that not everyone does/could or should receive a confirmed diagnosis, so this is not about recording a diagnosis for everyone. We are saying that when specific diagnoses are confirmed (for long term neurological problems) e.g. Huntington’s, Parkinson’s, epilepsy, motor neurone disease (MND), multiple sclerosis (MS), and then these should be recorded on TRAK.

Why is this in the plan?

- From the outset of this planning process a key priority of joining up care has been identified.
- We also identified that it was important to know who we are looking after – both in planning/population terms i.e. knowing how many people and a bit about them and in terms of clinical care.
- We have an aspiration to use patient based data for research, planning and clinical care provision.
- We have seen that services are provided by a network of sectors/teams etc – and that’s just within the NHS. A single patient record and care plan is essential if care is to be joined up and patient centred and the starting point for this is identifying and developing the possibility of a register of patients of shared interest.
- Information on numbers of people, patterns of care or better still outcomes and problems should be the basis of demand and capacity planning.
- This is a simple first step towards building a shared patient record.

What do we need to do?

Communicate the purpose and scope clearly then agree a mechanism for achieving this.

b) When a confirmed diagnosis is made and recorded on TRAK ensure there is a referral to the appropriate nurse specialist/pathway administrator or, where applicable, holder of the register.
c) Consider whether other conditions/care pathways could benefit from this approach

2.2 Review of medicine

Why is this in the plan?

We need to introduce e-triage and maximise this as a way of managing and monitoring demand on the service, not just in terms of referrals from primary care and outpatients, but potentially in terms of referrals from other specialties. Demand management is an important clinical activity and may need time.

There is a continued use of waiting list outpatient clinics, indicating that capacity and demand are not matched.

We know that neurology and neurosurgery have potential to contribute to care unscheduled care flow, and care in other specialties particularly general medicine.

We know that there is already debate about models of cover for the DCN wards and we also know that there is an on-going problem because of demand from other specialties for these beds – which in turn disrupts scheduled care and requires yet more management capacity to be devoted to managing problems rather than moving forward service improvement – and furthermore we know that there will be patients in other beds (not necessarily those placed there) who would potentially benefit from neurological/neurosurgical care.

We know that there is constant debate about contribution to the stroke rota. NHS Lothian Director of Scheduled Care has commissioned a review of a model of acute stroke care based on the option of acute stroke care in Edinburgh being based on the RIE site.

We know we need to have a model of acute neurological and neurosurgical care which is effective and efficient and maximises the opportunities (and minimises risks) of the move to the new DCN.

We know that there is potential to help with all of the above by having clear pathways of care in place that are led and reviewed – so we may well need consultant capacity

We know that we aspire to develop leadership and management of pathways of care - particularly for pathways of care which are high demand and or acute (unscheduled) across the system as a whole as well as in neurology/neurosurgery – headache, head injury, seizures/syncope and epilepsy, functional symptoms, low back pain.
We know that we have aspirations to develop multidisciplinary teams, and fully implement pathways of care for example in relation to functional symptoms - and to extend care provision in other ways.

We know that we have aspirations to deliver a different relationship with patients and with other professionals and medical staff are key to this.

We are aspiring to excellence in teaching and research, but seeking to make sure that NHS and academic priorities are complementary and add value, again medical staff are key to this. There may be potential to increase amount of training in out-patient/community liaison settings?

If we have not looked internally to reshape demand capacity and resources why would we think we can ask for additional resources to achieve our aspirations especially when resources are so limited?

**What actions are needed?**

E-triage should now have commenced – this will need to be reviewed and the implications considered for further development – both in terms of managing demand and shaping capacity and in terms of time.

We need a clear statement of what the medical service is. There have been some discussions about the shape of the medical service and how consultants are working, but lack of a full consensus has meant that these have not been implemented.

We need to agree pathway leads.

We need clarity on the model of acute neurological and neurosurgical care – this relates to DCN redesign also

We need to capture all activity more accurately.
2.3 Clinically focused review of the structure of outpatient capacity

Why is this in the plan?

As noted above, neurology continues to rely on additional outpatient clinics to try and deliver waiting times targets.

Although there is “generic” efficiency work underway – and this is essential – for example centralised booking procedures and processes, reviews of protocols for patient focused booking, introduce different ways of delivering contacts (telephone clinics etc) and seemingly endless counting of the numbers of people - we know that efficiency alone does not deliver strategic shifts, or improve patient care for that matter. We also know that there can be inefficiencies from “blanket” efficiency approaches and one size fits all thinking. Some people might describe these types of activity as reshaping demand rather than managing it.

A complementary approach would be to look at demand in terms of patient need and quality of care - segmenting the demand in terms of need or pathway.

The current version of the Strategic Plan includes a proposition in relation to scheduled care to reduce return outpatient appointments by 50%.

Given that we know that around half of new referrals are for epilepsy, headache and functional symptoms, (MS a close fourth in frequency) not having robust pathway management in place for these conditions seems a particular omission.

By knowing more about the populations of patients that we are looking after and having pathways of care in place, there will be opportunities to estimate capacity required for care and design capacity and approaches appropriate to patient need. It may even be possible to provide care for people with known conditions outwith the referral/waiting time/out-patient appointment systems altogether.

By managing demand in a different way, it may be possible to release management time from “waiting times efficiency pressures” to support proactive service improvement.
What actions are needed?

We need to implement the actions identified in relation to these key care pathways i.e. headache, epilepsy and functional symptoms. There is a proposal for implementation of a pathway for functional symptoms (Appendix 8)

Review of e-triage:

It’s great that a standard letter to GPs has been agreed so that referrals for headache which are appropriate for management in primary care receive a helpful but standardised response.

It would be good to monitor referrals pertaining to these conditions/symptoms automatically if that were possible

We should develop demand and capacity plans for these conditions separately as well as the overall DCAQ plan (Demand Capacity and Activity Queue)

There is potential to prioritise outpatient capacity differently – either in terms of special clinics or numbers of appointment slots for specific conditions in general clinics. This should be explored and pursued.

2.4 Development of liaison function – A and E and other specialties

Why is this in the plan?

As mentioned above, we know that there is significant potential for neurological and neurosurgical expertise to support improvements in patient care, and cost-effectiveness in other specialties, particularly general medicine and the emergency department.

There has been an estimate that there is value in neurologists confirming or making de novo neurological diagnoses in revoking or changing around a fifth of emergency or general physicians neurological diagnoses and in reducing length of stay in hospital.

For example, although there has been a weekly prospectively covered Rapid Access Neurology Clinic at RIE since 2007, a large audit (Chapman et al) showed that this does not sufficiently meet the need for consultant-led neurology input at RIE where referrals come from A and E, Combined Assessment Unit and ward referrals. We still do not appear to be meeting the demand at RIE and clinical experience indicates that further neurology involvement could shorten patient length of stay, avoid unnecessary investigations (especially CT brain) and improve patient’s management.
Additional neurology consultant appointments are unlikely, so the questions are where does this sit in the overall priorities for use of our limited capacity and consultant sessions and what could be done within existing capacity if we planned to deliver this function differently – see Section 1.2 above on review of medicine.

We note that clinicians form neuro-rehabilitation medicine actively visit RIE to identify appropriate patients who are most likely to benefit from rehabilitation.

**What do we need to do?**

Revisit opportunities for improved neurology liaison at RIE, looking ahead to the DCN reprovision on site and start to better quantify demand.

Consider the opportunities for neurology at the front door to contribute to a reduction in emergency admissions.

Bear in mind opportunities to improve liaison with neuro-rehabilitation.

Take stock of system wide pathways and patient flows in relation key presentations namely

- Headache/head injury
- Syncope
- Low back pain/trauma
- Seizures

**2.5 Development of rapid access 24/7 response (model of acute care)**

**Why is this in the plan?**

The sections above outline some of the issues in relation to patient pathways for unscheduled care across the system and the impact of neurological/neurosurgical problems (or potential for neurological/neurosurgical input). The issue of rapid access 24/7 response /model of acute care is slightly different.

For all areas of care the issue of timeliness is crucial – that is ensuring maximum effectiveness and efficiency for immediate care and/or managing urgent care (which can mean scheduling patients with emergency presentations into a planned response slot such as next day appointments/rapid access clinics or consultations). Alternatively, if there is capacity because of provision for rare need for immediate care – are there ways that the cost effectiveness of this capacity can be maximised by extending its scope to deal with some additional emergencies there and then?
The plans for a new DCN include an acute area, in line with the vision that unplanned workload be managed in a single area to protect and improve the scheduled care environment and activity. The reprocision team tasked with the development of the new DCN are clarifying the new model of care and associated capacity that will be made available.

There are concerns that the move to RIE site will result in an increase in demand on DCN, with expectations that the service will deal with more emergency cases when this is unnecessary and or inappropriate for a regional neurosurgical service, as patients with these needs have been, to date, treated appropriately elsewhere.

What do we need to do?

Work with the DCN Redesign Group to agree a model of acute neurological and neurosurgical care 24/7.

Agree staffing model for new DCN acute area over 24/7 which will seek to include:

- Identify current out of hours activity/emergency activity
- Understand function of rapid access clinics and consider in relation to acute care area
- Review model of provision of care for head injury management

2.6 Development of Parkinson’s Services

Parkinson’s disease (PD) is the second most common neurological condition and the most significant movement disorder.

PD is a complex progressive, degenerative disorder characterised by both motor and non-motor problems. The four key motor features of Parkinson’s disease are rest tremor, muscle rigidity, slowness of movement (bradykinesia) and postural instability. Although motor features define the disorder, there is a wide range of non-motor problems including autonomic dysfunction, cognitive and psychiatric changes, sensory symptoms and sleep disturbances. Up to 50% of people with PD develop cognitive impairment or dementia, and depression affects a similar number of patients. People with Parkinson’s have a high rate of falls, fractures and hospital admissions which could be reduced by early regular and timely intervention (Reference – Bloem BR, Munneke M. Revolutionising management of chronic disease: the ParkinsonNet approach. British Medical Journal 2014; 348: g1838). Mortality rates are twice those of the age standardised general population.

Medical care alone is insufficient, yet patients often have no access to allied healthcare provision (Parkinson’s Audit 2009, Parkinson’s UK). Parkinson’s
should be diagnosed by a neurologist or consultant with a specialist interest in Parkinson’s. Most patients are followed up long term by hospital specialists or the nurse specialist team particularly if complications occur and multidisciplinary support is needed in addition to drug therapy. When diagnosed with Parkinson’s disease, following the diagnosis being given to the patient, the confirmed diagnosis for all OPD patients should be entered onto TRAK as a coded diagnosis.

The prevalence of Parkinson’s disease in industrialised countries is estimated at 1.4% of the general population. The median age of onset is 60 years and the incidence of the disease increases with age, from 17.4 in 100,000 person years between 50 and 59 years of age to 93.1 in 100,000 person years between 70 and 79 years. Due to the ageing population, the prevalence is increasing year on year in western populations. There are four recognised stages of Parkinson’s disease: The diagnostic phase (11% of patients), the maintenance phase (40.5%), the complex phase (33.5%) and the palliative phase (15%). Parkinson’s specialist nurses (PDSN) have 1,700 patients on their files but estimate a catchment population of nearer 2,500.

In Lothian, the majority of the services for people with Parkinson’s are led by the medicine for the elderly service working synergistically with the neurology service. Substantial work has been undertaken over the past few years including the establishment of a Lothian Parkinson’s Service Advisory Group (LPSAG) which has developed a clear set of aspirations for an ideal Parkinson’s service (Maguire 2013), many key elements of which are applicable across other conditions and therefore have been included in the integrated generic care pathway.

The LPSAG committee includes representatives from medicine for the elderly, neurology, psychiatry, general practice, allied health professionals, nurse specialists and representation from Parkinson’s UK and the Edinburgh Branch of Parkinson’s UK.

The LPSAG was successful in establishing additional nurse specialist posts, bringing the total to three specialist nurses. The Parkinson’s Specialist Nurse Team integrates the network of care for people with Parkinson’s in Lothian.

**Vision of the service for Patients with Parkinson’s Disease in Lothian**

A vision for the ideal service for people with Parkinson’s in Lothian, spearheaded by the LPSAG was used to develop the generic integrated care pathway.

The key points of the vision include:

- Parkinson’s is important because of it’s prevalence and the co-morbidities associated with the condition.

- Specialist service standards are needed as local GP practices see a large number of patients, but each GP may only see one person with a new diagnosis of Parkinson’s every two years. The diagnosis of
Parkinson’s is a clinical one and is unique in that it combines a myriad of motor and non-motor features.

- The ideal service for people with Parkinson’s must be a multidisciplinary one - and this has been corroborated through the NHS HIS Neurological Standards, the SIGN guidelines for Parkinson’s and the NICE guidelines for Parkinson’s.

- Diagnostic error is common, particularly when patients are seen by non-specialists (error rate of up to 50%: 30-40% of cases may remain under-diagnosed). Diagnosis is particularly difficult in the elderly population (10% of institutionalised elderly).

- The ideal service for people with Parkinson’s would ensure that it has a person centred pathway, which would enable early detection of the condition with an easy and clear referral pathway. Early specialist opinion followed by a multidisciplinary assessment should take place with involvement of support bodies (eg Parkinson’s UK) throughout the pathway of care. The person with Parkinson’s must have easy access at all times to the Parkinson’s nurse specialist team and to the medical specialists. Continuity of care from diagnosis onwards and care should be joined up with specialists from all disciplines working together. There should be timely review by a multidisciplinary team with no discrimination based on geographical area.

What is present now?

**The Lothian Parkinson’s Service Advisory Group**
The multidisciplinary LPSAG meets, as part of NHS Lothian, to oversee and help drive the services for people with Parkinson’s in Lothian.

The LPSAG hosts an annual education forum meeting, to bring together and assist in the education of health professionals working with people with Parkinson’s in Lothian. The Parkinson’s nurse specialist team has developed a Learn Pro online teaching module on Parkinson’s Disease can be accessed voluntarily by all clinicians across NHS Lothian and which many health professionals have completed.

**EPAC**
The Edinburgh Parkinson's Assessment Clinic (EPAC), a therapist-led clinic for people diagnosed with Parkinson’s, was developed in Lothian to provide access to advice from a physiotherapist, occupational therapist and speech and language therapist. The aim of the EPAC service is to assist any person recently diagnosed with Parkinson’s to self-manage their condition by providing them with early education and advice. Any newly diagnosed person with Parkinson’s in Lothian may be referred to the clinic for assessment to ensure that advice is given as soon as possible after diagnosis. EPAC is currently held in the Assessment and Rehabilitation Centre (ARC) in the Royal Victoria Building at the Western General Hospital. Referrals are made directly to EPAC and can be from hospital specialists who have made the diagnosis, the Parkinson’s nurse specialists, or GPs. The EPAC clinic is a therapist-led
clinic with no medical presence at the clinic. Following assessment, a report is sent to the GP, hospital consultant and Parkinson’s nurse specialists with the result of the assessments and any recommendations made at the clinic.

**Clinics for people with Parkinson’s**
Across Lothian, there is a cohort of consultants (medicine for the elderly and neurology) with specialist training in the management of people with Parkinson’s who run specific Parkinson’s or movement disorders clinics. Referrals are made by general practitioners through SCI-Gateway to the neurology or local medicine for the elderly service depending on the age and needs of the patient.

Most patients who are seen by a specialist are subsequently referred on for review by the Parkinson’s nurse specialist (PDNS) team. The PDNS team also holds joint clinics with some consultant specialists, as well as autonomous new diagnosis and review clinics, and telephone consultations.

The PDNS team regularly review people with Parkinson’s who cannot access hospital services (eg those in care homes), and track and assess people with a diagnosis of Parkinson’s who are admitted to hospital.

There have been variable pockets of service excellence (medical/AHP) in Lothian, which have tended to be personality dependent and driven. There is a general lack of access to adequate AHP expertise and PD multidisciplinary teams. The patient journey is not always seamless, and a percentage of people with Parkinson’s in Lothian remain undiagnosed or lost to follow-up.

**Psychiatry / Psychology**
A consultant in old age psychiatry holds a regular joint clinic with one of the medicine for the elderly Parkinson’s specialists. The clinical psychology department also has a specialist interest in the assessment and management of anxiety in people with Parkinson’s.

**Physiotherapy**
There is a network of neuro-physiotherapists in Lothian for whom working with people with Parkinson’s disease is one aspect of their specialisation.

The Lothian Parkinson’s Physiotherapy group has identified that:

- 20-30% of the neurological outpatient physiotherapy caseload are people with Parkinson’s,
- Services struggle to provide timely intervention for PD despite prioritisation strategies.
The Parkinson’s physiotherapists have also identified the need to:

- Review staff competencies in PD.
- Identify specific staff training needs in area of PD.
- Set up dedicated PD intranet page to aid communication/access to key information.
- Review patient education throughout the journey and support the development of patients understanding.

**Day Hospital Services**

Many people with Parkinson’s aged over 65 years are seen regularly by the multidisciplinary teams within the area’s day hospitals, run by the medicine for the elderly teams.

The five day hospitals in Lothian: Assessment and Rehabilitation Centre (ARC) at the WGH, Liberton Day Hospital, Older Peoples Rehabilitation and Assessment (OPRA) at Leith CTC, St John’s Day Hospital, and Roodlands Day Hospital, provide multidisciplinary rehabilitation assessment for older adults (aged over 65 years) with a large percentage of those attending having Parkinson’s disease. Day hospital referral can come from GPs, hospital consultants, nurse specialists, and community teams including community therapists.

Patients normally attend for one day per week over a six week period and undergo a full multidisciplinary assessment. Many staff (nursing, medical and AHP) within the day hospitals have undergone training in the care of people with Parkinson’s.

**Speech and Language Therapy (SALT)**

There is also a network of speech and language therapists for Parkinson’s and the issues here parallel those in relation to physiotherapy outlined above.

An audit of SALT for people with Parkinson’s in Lothian identified 25 new referrals per month on average – extrapolated to 416 per annum – caseload average 95 people per month. The majority (77%) are seen by the community SALT team (around 16% of all people with Parkinson’s per year).

The Parkinson’s speech and language therapists have developed an evidenced based assessment toolkit with agreed outcome measures, which can be shared as patients move around Lothian services.

They have identified the opportunity to develop a standardised approach to group work for solution focussed brief therapy to support self management and active therapy tasks similar to those used in the Lee Silver Voice Training (LSVT) across Lothian.
Other plans include:
- review equipment
- develop a training strategy – Parkinson’s’ resource pack on SLT shared drive SALT study session
- competency framework and to
- consider steps which will increase our ability to offer LSVT, how we may provide early dysphagia rehabilitation, develop and act on user feedback.

**Occupational Therapy**

Most of the occupational therapy needs of people with Parkinson’s are generic and similar to others with chronic neurological conditions. There is an occupational therapist as part of the Edinburgh Parkinson’s Assessment Clinic (EPAC) based in the Royal Victoria Building in the Western General Hospital, who provides assessment and advice to those who have recently had a diagnosis of Parkinson’s.

**In conclusion**, at present, allied health professionals with specific skills in neurological rehabilitation are managed from a range of operating units across Lothian (community and secondary care), are few in number and, at present do not have the means of co-ordinating service capacity or care for the populations of people with neurological conditions or for individuals.

Our work on pathways for people with Parkinson’s is considering important evidence based models for integrated working from the Netherlands. This involved building networks of expertise and consolidating the care of people with Parkinson’s with clinicians within the network of expertise.

Whilst we develop integrated pathways of care for Parkinson’s as a specific condition, the general models and issues could apply to other conditions.
What do we need to do?

Parkinson’s is a condition that is unique, not just because it combines a variety of motor and non-motor symptoms, but also as it is best managed through the co-operative working of a multidisciplinary team including neurology, medicine for older adults, allied health professionals, psychiatry / psychology, general practice, and support agencies including Parkinson’s UK. The person with Parkinson’s must have early and continued access to this multidisciplinary team.

We need to consider if it is possible to risk stratify the population of people with Parkinson’s in more detail, in relation to specific therapies and interventions, and in relation to stages of the illness.

We need to ensure that people with Parkinson’s in Lothian have access to the most appropriate treatments for their condition, including non-pharmacological treatment, drug treatment and neurosurgical procedures.

We need to continue to support the existing Parkinson’s network (advisory group)

We need to formalise the leadership of services for people with Parkinson’s.

As with other conditions we need to record a diagnosis of Parkinson’s on TRAK – this is underway

We then need to develop use this information for planning and care delivery (eg being notified when someone with Parkinson’s goes into hospital).

We need to complete and fully implement the person centred pathway of care

We have the aspiration to improve early detection and recognition - we need some way of capturing achievement on this.

We need early multidisciplinary assessment - the implementation of the EPAC clinic is a good start.

We need to support the neurophysiotherapists and speech and language therapists working with people with Parkinson’s to develop and implement their plans.

We need to specify and plan provision of AHP input and this needs to provide continuity as well as integration within the MDT.

We need to consider how and whether the issues identified in the development of integrated pathways of care for Parkinson’s could apply to other conditions.
2.7 Development of neurorehabilitation services

Why is this in the plan?

Specialist neuro-rehabilitation services are provided by NHS Lothian Rehabilitation Directorate Astley Ainslie Hospital (AAH).

The overall budget for rehab Medicine is £17.2M but this includes the full range of rehab functions.

Services captured within this include:

- **Rehabilitation** £1,708,706 (presume this is other than in the ward/unit budgets but includes orthotics and smart centre)

- **Lanfine unit** £923,367

- **Robert Fergusson unit (RFU)** £2,154,213 (National Brain injury unit)

- **Brain injury unit** £2,100,733 (also a national unit)

The IRF data analysis undertaken at March 2013 showed that the health and social care delivered clients incurred £2,911,523 of costs in neuro-rehabilitation. This method includes in-patients so presumably would encompass the costs of Lanfine Unit and Lothian patients in RFU/brain injury unit , accounting for the majority of the £2,911,523 of costs.

We have information on the activity of the neuro-outpatient service, and this shows that this small service currently sees only 6% of people with MS, 4% of people with Parkinson’s and 4.2% of people with (moderate to severe) brain injury per year.

We have limited information on psychology and AHPs numbers/costs or activity in relation to Lothian patients. This excluded speech and language therapists who carried out an audit and physiotherapy who carried out a scoping exercise, clearly identifying the neurophysiotherapy outpatient services The fragmentation of the services is presumably one of the reasons we don’t have this – though if we recorded diagnoses on trak we could start to collate this information.

The Lanfine Unit is undergoing major redesign – shifting from an in-patient models of care (26 beds at Liberton) to an interim position with 18 beds at AAH with the intention that the resources freed up from a further the reduction in beds is used to develop a range of services including a breaks from caring fund, Carer support and a multi disciplinary outreach services which will offer direct alternatives to in patient treatments.
In terms of the use of in-patient resources we know from experience that the absence of appropriate supported accommodation or residential accommodation in community settings can delay discharges – particularly for younger adults with complex neurological conditions.

Planning is underway to reprovide the REH and this includes in-patient neuro-rehabilitation resources.

Irrespective of the issue of capacity and activity – what we do know is

a) We have no evidence that the services were designed as part of an integrated approach to meeting the needs of known populations of clients
b) It’s not clear how the roles of the different units and teams in rehabilitation integrate, nor are the pathways from secondary/acute care clear
c) There doesn’t appear to be a unified vision for rehabilitation which captures the functions (across the spectrum of care from neurobehavioural – neurocognitive – and physical rehabilitation) and scope of integration so that teams are “more than the sum of their parts” and effectively balances an impairment and diagnosis based approach – a single team which is community orientated.
d) Access to rehabilitation services is by referral – including referral from DCN consultants and there is no shared record of care or MDT approach (across DCN and rehabilitation) to care planning – though individuals make the system work.
e) There is an aspiration to have a single point of contact for neuro-rehabilitation
f) Neuro-rehabilitation has not formally included care for people with functional symptoms or ME-CFS although a pilot service delivered from AAH in 2014 is currently being evaluated.

We also have an intermediate/specialist local rehabilitation resource in West Lothian, CRABIS, which is highly regarded and may offer a model of care which could provide a template for service development in local partnerships.
**What do we need to do?**

We need to have shared patient records and care plans across NHS Lothian for clients with known on-going neurological conditions

We need to ensure the clinical brief for rehabilitation services in development with services currently provided on the AAH site will provide model for the whole of specialist rehabilitation services

We need to confirm the timescales for implementation of the Lanfine outreach team and the service specification for this

We need to confirm the service specification for the Lanfine outreach team – in particular to confirm role of existing specialist nurses in case management

We need to collate activity and staffing information

We need to understand the finance and content in relation to the “national units” RFU and Charles Bell

As per above – a key priority is developing models and capacity plans for the delivery of AHPs and psychology

We need to work with local partnerships to plan supported residential care/nursing home capacity for people with neurological conditions and complex needs

As per issues on organisational development we need to build a shared infrastructure and multidisciplinary team working across rehabilitation and DCN (stroke and neurology in general medicine) to consolidate pathways and make delivery of improvements across the system more “effortless”

We need to consider the potential to develop a single management structure across DCN and rehabilitation

We need to refresh our plans for the development

We need support and plan for an extension of scope of rehabilitation in relation to brain injury, functional symptoms

We need to consider support for postural management as an integrated function of specialist rehabilitation services

We need to learn from CRABIS, share the learning and encourage development of services in local partnerships
2.8 Development of neuropsychology and psychological services and interventions

Why is this in the plan?

Access to neuropsychology is currently inadequate. For the past few years, there has been a single neuropsychologist supporting DCN.

There is now a single management arrangement in place for psychology across DCN and neurorehabilitation – and this brings opportunities to understand provision and care across both these sectors. It’s for that reason that neuropsychology and psychological services appear in the “sector /management unit” part of the plan (other AHPs don’t have a joined-up management arrangement so appear in cross cutting themes and pathways).

Psychology for people with Parkinson’s is provided through psychology for older people, and some psychology support is provided in clinical genetics for people with Huntington’s.

A few of the reasons why psychology is integral to the plan and the delivery of all neurological and neurosurgical services, improving the efficiency and effectiveness of services overall:

• For diagnostic assessment – improves diagnostic accuracy, speeds diagnostic process, avoids unnecessary and unhelpful appointments, interventions and investigations, key element of effective treatment

• Assessment of current abilities – supports MDT in their assessments and delivery of treatments including capacity to make decisions – key element of effective rehabilitation which facilitates safe and effective discharge and improves outcomes for patients

• Pre-surgical assessment – determine suitability for neurosurgical assessment including risks to cognitive function, potential cognitive function after surgery

• Assessment of medical procedure outcome – allows effectiveness of interventions to be monitored leading to better patient safety

• Prognostication – determination of likely recovery - better care planning and communication with patients and families

• Provision of cognitive rehabilitation and emotional adjustment

• Behaviour management
What have we done?

We have recruited to the DCN neuropsychology post and some short-term funding has been made available for an additional psychology post.

We have enhanced the provision of neuro-psychology attached to the Lanfine service.

We have identified that the previous neuropsychology post had evolved a role over time, but with limited resources there was no service specification, no specific clinical space or recorded processes for referral or clinical activity. The post had only a few hours administrative support. As a consequence of there being only a single post, there is no record of need or demand, as many clinicians assumed that the service was available for limited cases.

We have developed a neuropsychology matrix of interventions (Appendix 7)

We have developed a stepped model of care for neuropsychology.

What do we need to do?

As part of this stepped model of care we will need to ensure that other disciplines have the tools and skills to undertake some psychological interventions – in particular build on the work that specialist nurses are already undertaking.

We need to use the neuropsychology matrix and the information on patient numbers to specify the service that can be offered more clearly, and this needs to include details of how clinicians refer to the service and who to refer.

We need to identify resources, access to clinical space, IT and administrative support to fully integrate the psychology service within DCN.

We need to take a deep breath, bear in mind the capacity we have available, and look at the matrix/steps and each of the pathways of care, estimate demand, prioritise and quantify gaps. Gaps identified already include assessment and early intervention for people with “moderate” brain injury and for management of complex functional neurological symptoms.
2.9 Development of neurophysiology and diagnostic services

Why is this in the plan?

The NHS Lothian neurophysiology service consists of a range of diagnostic procedures provided at two sites and provides a tertiary referral service:
- Adult service at Western General Hospital (WGH)
- Paediatric service at Royal Hospital for Sick Children (RHSC)

Currently core staff are based at each site, with rotation across the supra regional service to maintain skills in differing adult and paediatric procedures and to cover the exigencies of the Supra Regional Service.

There are currently eight main categories of Neurophysiological investigations provided in the adult service, which are all demand driven across both in and outpatient referrals:

- EEG, incorporating sleep deprivation, and intra operative recordings carried out in Neurosurgical theatres. There is approx a 60/40 split between elective outpatient’s referrals and in patient requests.
- Portable EEG recordings in ITU/secure units across Lothian and in patients who are unable to travel to the Department across Lothian. The demand for this urgent service has risen exponentially over the last 5 years.
- Evoked Potentials
- Video Telemetry: for which activity is demand driven. This can be for diagnostic purposes but can also be used as part of the surgical workup for the treatment of patients with intractable epilepsy.
- Electromyography- performed by the consultant Clinical Neurophysiologist and is mainly elective outpatient service with a 90/10 split between out patient and in patient referrals.
- Nerve Conduction Studies: for which activity is a function of capacity available, both clinic rooms and from any remaining Physiologist capacity after EEG / Evoked Potential demand is met.
- Adult intra-operative monitoring is largely an unmet need from the Neurosurgeons at the WGH and orthopaedics at the RIE site. The service would be appropriately enhanced with the availability of out of hours on call as well as an elective service. The paediatric service is funded by National Services Division and delivered from the RHSC site as part of the National Service for the Surgical Treatment of Paediatric and Adolescent Scoliosis.

Neurophysiology investigations feature in many patient pathways, including referrals from neurology, neurosurgery, intensivists (a physician who

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5 Following reprovision in 2017 the departments will amalgamate but retain 2 separate recording areas, one in the paediatric setting adjacent to ward 7 and the main department and review area, adjacent to the adult neurological wards on the floor below. This will allow some consolidation of current staff resource.
specialises in the care of critically ill patients), care of the elderly, learning disability services, orthopaedic, rheumatology, plastics.

A detailed report summarising the gaps in capacity and demand for each of these interventions is available. This includes current performance against referral to treatment (RTT guarantees), options to achieve these.

The report contains a clear statement of workforce development requirements and issues.

It also includes a “horizon scan” of interventions that we are aspiring to provide.

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### Generic/cross cutting developments

#### 2.10 Involving patients and carers

At the moment we have two development areas in relation to this.

- Working with Neurological Voices
- Developing a website

**Why are these in the plan?**

Involving patients and carers or working in partnership - is one of the aims of the Strategic Clinical Framework and key part of our vision.

A fundamental transformation of health care will only be delivered by delivering a different relationship with patients and the public engagement through different media and e-health, different communication, active de-escalation/deintensification of care processes in line with patient priorities. We know for example from the stakeholder workshop that patients expect to be able to communicate with clinicians using new media, to avoid unnecessary hospital attendances but have rapid access when needed.
Neurological Voices

NHS Lothian in partnership with the Scottish Neurological Alliance supports a Lothian Voices group which includes representation from patients and carers, committed to working together to improve care and services for people with neurological problems across Lothian. This group has ensured that the development of this plan has been consistently informed by the voice and experiences of patients and carers.

We also know that communication is fundamental to a therapeutic relationship, and that the therapeutic relationship is fundamental to positive outcomes and that the clinical skills and tasks required differ in different contexts. Current work with the NHS Lothian Strategic Plan and the House of Care model includes a focus on patient outcomes from positive consultations. This is now forming a consistent theme in the implementation of this plan across integrated care pathways.

This broad ambition therefore demands changes in administration (efficiency), developments in IT – but it also requires recognition of the clinical meaning and the different clinical skills required. This issue therefore reappears in sections on IT, but also clinical leadership.

In terms of developing a website, the reasons for doing this are:

- Internet presence is an integral part of service provision and communication.
- Patient centred services means patient centred internet sites.

Perhaps the main reason though for including this in the plan is the added value that it will deliver: in order to produce a website we have to understand and articulate what services we are providing, so this process in itself identifies gaps and issues.
2.11 Workforce development plans

Why is this in the plan?

The network of services is complex. For some professional groups with specialist skills there seem to be as many management lines as there are posts.

In recent changes and reviews some key posts have been lost, and in retrospect it does seem as if the absence of a clear statement of the needs of this population and lack of an overview may have meant that the value of these posts has been unrecognised.

We know that there is a current fashion for genericisation on the (untested) grounds of flexibility and affordability, but our stakeholder workshop identified the importance of balance between specialisation and generalism and our vision emphasises the importance of specialist skills.

Part of our vision for excellence is to have multidisciplinary team working joined up around individual patients and patient groups.

There are major developments ahead which will require workforce development plans – the new DCN – which as we know will require a costed

What do we need to do?

We need to continue to support and develop Neurological and Neurosurgical Voices and ensure the contribution to the Leadership group continues to be embedded.

We need to consider the role of Neurological Voices, not just in relation to service improvement, but also in relation to research so we need to briefly consider whether there are synergies here.

We need to make sure that the priorities of users and carers are included in the plan.

We need to develop a “plan within the plan” in relation to developing the involvement and engagement with users and carers in service delivery and in research whilst recognising that there is already a lot of information about patient’s views and experience available if we found ways of using this.

We need to look at the different aspects of “delivering a different relationship with patients and the public”

We need to develop and maintain a website for the public which has information on the services we provide – this is underway.
model for nursing and a staffing model for the acute area. Earlier sections of this plan (DCN sector) identified the need for a review of medicine.

Plans for neurorehabilitation – the REH re-provision or current work on redesign of neurorehabilitation also require workforce plans.

The right workforce capacity (skills and service capacity) is a fundamental for the delivery of the integrated care pathways.

It’s clear at the moment for some key professions – particularly AHPs that, if designed at all, are not designed in a manner that meets the needs of patients on a systemic basis.
What do we need to do?

Some excellent work is underway and earlier sections of this report have referred to some of this. Taking all the elements of work underway the unifying themes are:

- A matrix of interventions for each discipline, speech and language therapy, physiotherapy and occupational therapy (if necessary specified by impairment or diagnosis within the matrix of interventions)

- Clarify the stepped care model

- Consider numbers who need/would benefit from each intervention and level of specialisation for delivery of that intervention

- Ensure that models include capacity to build capacity in generic services

- Seek to provide a single service across the whole of Lothian and across settings in terms of access, outcome measurement, assessment, training and sharing activity – as a minimum ensure that there is a single pathway across the whole of Lothian

- Establish baseline numbers of referrals/activity

- Develop shared tools for assessment, support and outcome

- Develop plans for training

- Develop plans for patient education

- Seek to ensure that all people with a confirmed diagnosis of a neurological condition receive a multidisciplinary assessment at the point of diagnosis and that a single care plan and record of care is in place

- Remember that establishing a single service by discipline or a single pathway by discipline does not necessarily facilitate multidisciplinary working

- We need to continue and develop with work with Parkinson’s UK on models for excellence and maximise their offer of development project support in relation to neurophysiotherapy for Parkinson’s.
2.12 Medicine

Why is this in the plan?

Earlier sections of this plan have touched on the issue of review of medicine in DCN, so this section focuses on the general issues.

When referring to medicine, this means across specialties and potentially primary care.

What we need to do?

We need develop medical leadership to deliver a different relationship with patients – in recognition of the changes to clinical skills and confidence and governance required by different ways of communicating and relating to patients.

We need to formalise medical leadership for pathways and articulate clearly what this means – the role may differ depending on scale and complexity and we should recognise that overall clinical leadership could come from another discipline.

We need to formally agree a lead consultant for all people with symptoms of Huntington’s Disease

In general we perhaps need a different model of being a consultant. If we want to transform the delivery of care we need to build different ways of being a consultant into job plans. The job planning process currently focuses on direct patient care – but defines direct patient care in traditional ways such as outpatient clinics. In seeking to make sure we provide more direct patient care we have sought to move from 2.5 Special Programmed Activities (SPA) in a job plan to 1 SPA. An alternative approach would be to consider the development of “indirect patient care” as a valuable SPA.

2.13 Administration

Why is this in the plan?

We now know there is a relatively small population of people with long term and complex needs, requiring considerable on-going or sporadic input from DCN and neurorehabilitation (specialist, general community and social care) services across our fragmented system.
We know that we have a large number of points of administration for patients. That our vision recognises that:

*Good care needs high quality in all aspects of service provision from administration to clinical communication.*

We know that we have a tendency to refer to reducing administration as one of our popular cost efficiency approach, when there are opportunities for efficient and effective administration to be part of the clinical and care process, support efficiency and navigation and produce better outcomes for patients.

We know from reports that for those patients with access to nurse specialists or specialist advisers, these roles are valued as crucial navigators and coordinators and undertake considerable administration tasks as part of this function, though they have inconsistent and limited access to administrative support.

We know that we are aspiring to a single point of referral for neurophysiotherapy and can see the potential for a single point of referral for both neurological occupational therapy and speech and language therapy. We can see then that a single point of referral for all therapies has the potential to facilitate multidisciplinary working and co-ordination.

### What do we need to do?

We need to develop an administration “hub” for the specialist nurses/specialist advisers.

We need to actively consider the possibilities of extending the functions of this hub to be a single point of contact for a) all known neurological care and neuro rehabilitation patients and b) for all specialist nursing/therapist referrals and c) all neurological care follow up referrals.

### 2.14 Specialist Nursing

#### Why is specialist nursing workforce in the plan?

We also know from our stakeholder conference, the prioritisation exercise undertaken by Neurological Voices, wider published evidence and evidence developed locally that the nurse specialists are a core asset in an integrated care pathway, particularly in terms of joining up and co-ordinating care for individuals and for maintaining an overview of the needs of patients with specific problems and conditions. In the national survey of patients, it was also clear that specialist nurses are highly valued as a point of contact.

By way of reminder there are nurse specialists/specialist care adviser roles for Motor Neurone Disease, Huntington’s (a nurse specialist and a care
specialist), subarachnoid haemorrhage, multiple sclerosis, epilepsy and Parkinson’s Disease.

There have been numerous reviews of specialist nurses, and by definition this broad review approach

a) takes specialist nursing out of the context of their patient groups
b) takes specialist nursing out of their context in MDTs and multidisciplinary services, and
c) perhaps are not sensitive enough to the blend of functions which specialist nurses provide.

Specialist nurses have a range of different management lines: DCN, clinical genetics and medicine of the elderly and are embedded in MDTs or pathways differently.

Having discussed the topic of specialist nurses with management colleagues in primary and community care, there seems to be reflex response along the lines of “yes but they should be in the community” – answer “they are in the community but perhaps you’re just not aware of this”, and, if we are thinking in a joined up way, this argument and line of thinking misses the point. Or to put it in terms of one of the five laws of integration$^6$ – one person’s integration is another person’s fragmentation.

There are also major (cost, complexity and volume: demand) pathways which have no nurse specialists – notably functional symptoms and headaches, though there is a proposal for implementation of a care pathway for functional symptoms.

$^6$ The five laws of integration (paraphrased): Whoever integrates calls the tune, one person’s integration is another person’s fragmentation, you can’t integrate a square peg into a round hole, integration costs before it pays, you can integrate some services for all people, and all services for some people but you can’t integrate all services for all people. I think the gist of this plan is that for people with neurological conditions we can and should integrate all our services.
What do we need to do?

Develop our understanding of the shared and different functions of specialist nurses in neurological care. We need to develop this forum and take forward the actions we agreed.

In particular:

- Maximise opportunities of TRAK and share expertise
- Develop consistency of activity recording
- Develop work with neuropsychology
- Look at different ways of communicating with patients
- Develop collaboration and consistency across the nurse specialist/care adviser roles

We need to develop the role of the existing specialist nurses in relation to developments in neuropsychology, neurophysiotherapy, speech and language therapy, OT and changes in neurorehabilitation.

We need to look for opportunities to re-build/strengthen a multidisciplinary team around the specialist nurses

We need to examine the potential for specialist nurse role in relation to functional symptoms and headache.

2.15 Neurological Nursing

Why is this in the plan?

Nursing plans for new DCN and REH/AAH reprovision are being developed.

We need a specification for the nursing contribution to the staffing model for acute care.

What do we need to do?

We need to ensure that all the work regarding the clinical brief for services affected by the new developments of the DCN and REH campus respectively will be addressing the nursing workforce planning issues.
2.16 Physiotherapy, Occupational Therapy and Speech and Language Therapy

We aspire to provide multidisciplinary integrated pathways of care. The as yet partial picture we have of these disciplines is that numbers of staff are small and that the services are fragmented.

Until we began the work on understanding who we were looking after, AHP staff had no overall view of their patient populations and each sector was responding to referrals. Key posts, for example a physiotherapist post which is linked closely with the Parkinson’s specialist nurse service and a physiotherapist post which was part of the MDT of consultant and specialist nurses have been lost. The AHPs working in neurological care do work as networks and physio and speech and language therapy (SLT) have undertaken significant work, but implementation requires agreement of all their different managers. See for example the diagram of care for a patient with Parkinson’s in Part One of the plan.

There are no consistent shared assessments or on-going care plans as services currently work individually on a referral and discharge basis.

These services that are available are highly valued by patients, carers and other clinical staff involved in care of neurological patients.

AHP services are fundamental to key performance targets – preventing admission, reducing out-patient attendances and ensuring effective discharge let alone health and social functioning.

Because of the extent of fragmentation, we don’t yet have a full picture of neurological activity, capacity or demand. But we do now have some parts of the jigsaw – we know that our neurological outpatient service see 6% of people with MS, 4% of people with Parkinson’s and 4.2% of people with brain injury each year. The SLT service audit showed that they saw 19% of people with Parkinson’s each year.

It would be good to have comparable information from other rehabilitation services.

Obviously we don’t know about people with neurological conditions who are accessing generic services and we should perhaps assume that this is necessary and appropriate. However when we looked briefly at the literature on neurorehabilitation for Parkinson’s - it seems that there would be good grounds to assume that 40% of people should have access to specialist neuro AHP services.
2.16.1 Physiotherapy

What do we need to do?

As per previous sections we need to develop plans for each discipline which include the following basic elements:

- a matrix of interventions for each
- a clearly defined stepped care approach
- a clear statement of existing specialist capacity
- progress on developing shared assessments and outcomes
- and of course everyone able to see shared patient records.

We need to remember that specialists can be specialists in terms of disciplinary knowledge and/or in the application of this knowledge to clients with specific needs. Specialist knowledge of the needs of clients can be common across disciplines.

What do we need to do?

The scoping document produced by the neurophysiotherapists clearly identifies a number of key issues

We need to support the neurological physiotherapists to implement their recommendations:

Improvements with accessibility (inequity of access, different service models, lack of clear pathways and possible duplication, problems of physical access and transport for people with complex disability)

Increased service capacity – there are currently only eight qualified neurological physiotherapists in Lothian

Changing models of service delivery and effective engagement in MDTs/integrated care pathways

Increased consistent quality of care – moving from the current position where there are “pockets of excellent practice and expertise”

We need to develop a matrix of neurophysiotherapy interventions and build on the stepped care model being developed by staff in the Lanfine

We need to encourage consideration of a single point of referral for neurological physiotherapy and a shared administrative structure, learning from the implementation of the musculoskeletal and back pain pathways – the single point of referral would provide us with information on demand.

We need to develop a stronger analysis of the need and capacity for neuro-physiotherapy.
2.16.2 Occupational Therapy

Why is this in the plan?

Neurological conditions are a major cause of complex and physical disability and occupational therapy assessment and/or support to achieve the highest level of function and independence in physical and mental daily activities is a core discipline in neurological care.

In Lothian adult NHS occupational therapy services are managed in four sectors: East Lothian and Midlothian (currently a single service across both areas), West Lothian, Edinburgh (including rehabilitation services at the Astley Ainslie Hospital, Liberton Hospital and the Robert Ferguson Unit) and the Acute Hospitals (Western General Hospital, Royal Infirmary Hospital and Royal Victoria).

At present the occupational therapy capacity with expertise in neurological conditions is focused on in-patient care (DCN and in neurorehabilitation) and accessed via medical referral. There is some positive collaboration across DCN and neurorehabilitation, with medical staff acknowledging the expertise of AHPs generally and OT specifically in identifying and supporting patients for rehabilitation. There is clear recognition of the potential to develop this collaboration and identify people and plan in advance for rehabilitation and reintegration into the community.

The development of pathways of care for people with stroke has included occupational therapy and this has brought into focus the developments required for people with (other) neurological conditions.

There is OT within the multidisciplinary neurorehabilitation out-patient team. At the AAH and within the CRABIS service in West Lothian. For the majority of people with neurological conditions who are not in-patients, provision of OT is through the generic community OT services.

In neurorehabilitation services, work is underway to integrate services and therapies across the neurorehabilitation specialties and units and to develop capacity for outreach and out-patient support (for example the development of the Lanfine outreach team).

There is recognition within the discipline of OT of the need to develop neurological health OT expertise and to shifting the balance of care to

- Community and out-patient provision – maintaining clients’ integration in communities and in employment
- being proactive - averting crisis and planning from the point of diagnosis
- providing improved access
- considering mechanisms for self referral, telephone consultation with stronger multidisciplinary networks
2.17 Pharmacy

DCN has a budget of around £4M per annum for drugs expenditure, approximately half of this (£2M) provides the risk sharing scheme for multiple sclerosis. The remaining £2M “core” drugs budget is growing rapidly and covers new disease modifying drugs and high cost, high risk, low volume medications used in an acute setting.

Medication has a major impact on the health outcomes for people with acute and on-going neurological conditions. For people with progressive neurological conditions, drug developments are a major source of hope though current drug regimens demand complex management and balance of risk and side effects over benefits. Monitoring and dispensing of specific medications is a key driver of out-patient contacts and attendances.
Despite the fact that we know that many of the people who receive treatment in DCN will either be known to have a neurological condition prior to admission, or require on-going neurological care following admission, there is no single pharmaceutical record for individuals, nor a single neurological pharmaceutical record for medications used in relation to neurological conditions. Use of emergency care summaries (GP) on TRAK which contain a list of current medications is an important development, but these may or may not be complete and accurate. If (some) Nurse Specialists keep records of patient’s medication, these are not routinely available to pharmacy, GPs or ward staff.

Pharmaceutical care in DCN (in-patients and out-patients) is provided by a single senior clinical pharmacist. Pharmacy support for rehabilitation services is from REH/AAH pharmacy services and for people with Parkinson’s from medicine of the elderly pharmacy.

There is no pharmacy overview of primary care prescribing for neurological conditions and identifying costs by drugs remains problematic because of the application of drugs in this category of the British National Formulary – drugs which act on the central nervous system – to other medical conditions.

Some primary care prescribing for neurological conditions will be covered by shared care protocols (maintained by DCN senior clinical pharmacist).

The potential for the development of pharmaceutical care for people with neurological conditions in DCN has been highlighted in a number of reports and proposals (quality improvement, risk management, invest to save) which have consistently highlighted the need to focus the limited pharmacy resource on high risk clinical issues in the in-patient setting. There are concerns about the adequacy of this resource even if this narrow focus were achievable.

In this context, the pharmacy capacity to support the development of multidisciplinary, system wide care and planning processes such as this (neurological care improvement) has been limited.

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7 Some medications for some specific conditions are closely monitored – for example the introduction of the MS Risk Sharing arrangement was a key driver for the development of Nurse Specialists.

8 Though it should be possible to estimate this using the IRF data for people identified as having neurological conditions if we can identify the people.

9 Data on drug expenditure for 11 major neurological conditions in Canada found that these neurological conditions (including Stroke and Alzheimer’s) accounted for 3.1% of the drug expenditure for all illness – a comparable figure for NHS Lothian would be £2.9M based on 2010-11 drug expenditure of £93M). To note this analysis found that drug expenditures accounted for about half of the direct health care costs associated with individual conditions of epilepsy, MS, Parkinson’s and Headaches, and Headaches accounting for half the drug expenditure across all these conditions. Although total direct health care costs were highest for stroke and Alzheimer’s, the proportion of costs accounted for by drugs was small 2.7% and 5.8% respectively and the total drug costs around half that of the drug costs for MS and Parkinson’s.
What do we need to do?

We need to ensure that the Neurological Care Improvement Group has a system wide overview of pharmaceutical care for neurological conditions.

We need to use this overview to understand what developments of systems, information sharing and collaboration and multidisciplinary working, if any, could reduce the demand on the limited clinical pharmacy resource.

We need to gain a better understanding of patterns and costs of medication use across the whole system, in particular to consider whether it is possible to identify and reduce the costs of prescribing for headache.

We need to understand the developments and thinking underway which may lead to a joined up information about patient’s medication use and see if we can expedite any of these.

We need to review the generic integrated care pathway and the reviews of condition specific pathways to explicitly include (or not) pharmaceutical care.

We need to review and pursue invest to save opportunities provided by the development of pharmaceutical care.

We need to develop a pharmaceutical care improvement plan for people with neurological conditions, particularly those with on-going conditions.

We need to build pharmacy capacity to support the wider multidisciplinary team to provide effective pharmaceutical care.

We need to learn from the work on the Parkinson’s pathway which provides alerts when people with Parkinson’s are admitted to hospital and which is seeking to ensure that when this is the case, Parkinson’s medication is administered at the appropriate time for the patient.

2.18 Social Care

We have begun the process of considering the key is sues in terms of social care.

We have used the Integrated Resource Framework to look at the health and social care costs of the cohort of people aged under 65 that we had identified as having a record of a neurological condition. This approach had particular limitations in terms of understanding the balance of care and resources across different conditions as the process of cohort identification required that people had an in-patient record. The summary of this analysis is contained in Appendix 4 of this report,” Statement of Resources Used to Provide
Neurological Care”. It identified social care costs of £21.6M. The costs refer to total social care costs, so could include care for other non-neurological problems and also the substantial number of people with epilepsy who have a learning disability.

Despite the limitations of the analysis, it reinforces that neurological conditions are the major cause of complex physical disability in younger adults.

We have recognised the value of informal and formal carers and the aspiration to ensure that they are appropriately trained to support people with specific conditions and appropriately supported to remain well themselves whilst also providing excellent care.

Work undertaken by Neurological Voices identified training (condition specific) for caregivers as one of their five priorities.

Our work on the pathway for people with Motor Neurone Disease noted the importance of rapid access to social care and this has now been addressed for Edinburgh.

We have considered the Edinburgh Community Stroke Service and West Lothian CRABIS (Community Rehabilitation and Brain Injury Service)\(^{10}\) and its role in West Lothian Disability Centre) in order to build our understanding of the issues to be considered in developing interfaces of health and social care and building pathways that integrate these.

We have noted that the development of networks of excellence must include social care services.

What do we need to do?

We need to strengthen the input from social care into the Neurological Care Leadership group work and ask the Joint Officers Group which support the Physical and Complex Disability Board to assist with this.

We need to consider developing neurological specialisation within social care provision as a means to achieve patient centredness and integrated working with health care.

We need to consider whether current “generic” social care processes, skills and capacity are “client centred”, that is whether provision based on sector team models provide appropriate knowledge and confidence and responsiveness for people with complex, progressive or sporadic neurological conditions, whether the tiers of social care provision match the tiers of complexity of need.

That said, we also need to take account of the overarching proves which is driving health and social care integration currently.

\(^{10}\) We identified the CRABIS service as one of our assets.
2.19 Research and innovation

Why is this in the plan?

We need to recognise the massive contribution made by our strong academic department, to research, service delivery, public / voluntary sector engagement and teaching and that, in return, the University of Edinburgh benefits from a strong NHS clinical department which carries out high quality research.

As we identified at the Stakeholder Conference, Edinburgh University is an international centre for excellence for neuroscience research incorporating regenerative neurology (within research on regenerative medicine) and within which the Anne Rowling Clinic and the Euan MacDonald centre sit; clinical brain sciences, including straddling neurology and psychiatry, prion disease (National CJD), stroke and paediatric epilepsy.

There is a long standing programme of work on functional neurological symptoms – which has informed part of this plan.

The Anne Rowling Clinic epitomises a commitment to service excellence and translational research which spans basic science and clinical care. The aspiration embodied in the centre, to advance science and build hope (of a cure for neurodegenerative conditions) is hard to connect with day to day life and priorities within the NHS, though it is of fundamental importance for patients.

We have identified an aspiration of developing routine data sets for all of research, planning and clinical care/service delivery purposes. Our common purpose is to improve patient care.

What do we need to do?

We need to sustain and develop the close and productive collaboration between the NHS and University of Edinburgh.

We need to consider whether there are opportunities in terms of:

- Infrastructure – IT, admin, and management within the university and within the NHS are necessarily different, but have we looked to see where there is a common purpose, whether we could achieve synergy and common purpose with greater integration?
- If we are thinking through developing our partnership working with the voluntary sector then couldn’t we give some thought and consideration to shared priorities with University of Edinburgh?
- We are aiming for multidisciplinary teams and service provision, but do not have a full picture of the scope of multidisciplinary engagement in research (and audit).

We need to bear in mind that we can identify opportunities to develop health services research in neurological care but that there is currently limited research capacity to undertake this.
2.20 Organisational development

Why is this in the plan?

We’ve already looked at how complex the management arrangements are for services around this relatively small but complex group (s) of patients. We have an aspiration to join up services. We also have an aspiration to develop ways of working which allow us to take a more proactive approach rather than fire fighting and to find ways to communicate and work together which are as productive and effortless as possible.

We have also identified that we need to build a shared and integrated infrastructure (technology and systems).

One of the basic building blocks of joining up care has already been identified: developing a single patient record.

This section seeks to identify organisational developments which support joined up working and service improvement in the course of day to day operational management, and which in theory, should pull together support functions and resources from across the wider organisation.

We suggest:

- Integrate DCN and neurorehabilitation through joint management approaches for neurology and neuro rehabilitation
- Develop modes of clinical communications – telephone consultations and advice.
- Establish pathway leadership and pathway monitoring and performance management
- Produce and deliver an e-health plan for neurological care
- Establish a joint Quality Improvement Team
- Improve process consistency eg clinic templates and administration

2.21 Integration and joint management approaches for DCN and neurorehabilitation

Why is this in the plan?

As noted above we are looking for ways to join up services and make that join up and proactive working as effortless as possible. It’s clear from the history of neurological care improvement work that adding a layer of meetings and work over and above operational management of the services is problematic, with key people struggling to attend and communication from the meetings to services requiring mechanisms that currently aren’t in place.
There are obviously important synergies particularly with neurosurgery and brain injury units as well as some of the outpatient services, and for people with long term neurological conditions. The rehabilitation services also have a key role in stroke rehabilitation, though the relationship between DCN and stroke services is under discussion.

In terms of configuration of services around patients with a high level of need these services are looking after the same, relatively small and potentially defined population, albeit that they may not know that because we don't have clinical joins in place in terms of knowing the numbers of people and having services designed to meet their needs.

We've already considered the fragmentation of AHP services and having shared patient records and knowing the numbers of people potentially makes it possible for a multidisciplinary team of AHPs working across settings with the all of these populations.

In developing integration we need to be mindful of the five laws of integration\(^\text{11}\) one of which is that one person's integration is another person's disintegration.

Some considerations include: there is also currently an identity to rehabilitation medicine as a whole which is positive though the services within rehabilitation medicine are currently quite fragmented and this is an issue that the neuro rehabilitation redesign is seeking to address.

We know that there needs to be clear pathways from DCN to rehabilitation and the planning for the new DCN and any reprovision of rehabilitation needs to tie together.

Although there are pros and cons of any model of management, and we know that management models rarely stay fixed for very long, there is perhaps a view that in a cycle of change and evolution we should join at different boundaries or integrate different boundaries according to context priorities.

Now is a good time to consider making the join at this boundary (DCN and rehabilitation) a key priority.

The strategic plan in development is emphasising an approach based on developing pathways of care for groups of people with shared needs. If we started from what we now know about the numbers needs of people with neurological conditions, would we design the organisation around them in a different way?

---

\(^{11}\) The Five Laws of Integration:

- You can integrate all of the services for some of the people, some of the services for all of the people, but you can't integrate all of the services for all of the people
- Integration costs before it pays
- Your integration is my fragmentation
- You can't integrate a square peg and a round hole
- The one who integrates calls the tune
What do we need to do?
We need to discuss integration of DCN and neurorehabilitation and joint management approaches that are deliverable in the short term and those that are aspirational for the future.

2.22 Establish a joint quality improvement team

Why is this in the plan?
One of the drivers for establishing a neurological care improvement group was the HIS Standards for Neurological care. These are whole system standards. Given that a key role of quality improvement teams is to monitor progress and achievement of quality standards it seemed appropriate that a single quality improvement team across neurorehabilitation and DCN could progress this agenda.

We have discussed this on a number of occasions and agreed that in principle it should be possible to have a joint quality improvement team perhaps running alternately with existing quality improvement teams.

In theory a joint quality improvement team should act as the point of reference for the development and monitoring of progress towards achieving the healthcare improvement Scotland standards. Failing the development of the joint quality improvement team then perhaps the Neurological Care Improvement Leadership group should ensure links with both the current quality improvement teams to progress work towards achieving the healthcare improvement Scotland standards.

What do we need to do?
We need to think realistically whether there is the resource and commitment to take the development of a joint quality improvement team forward and if not remove this from the plan.

2.23 Develop process consistency

Why is this in the plan?
There are a number of aspects to the issue of process consistency. Some of these apply within sectors and may apply across sectors, potentially for helping to join up across sectors. Process consistency is a key part of the implementation of integrated care pathways and earlier sections of the plans relating to capacity on demand management.
The different elements of process consistency include the development of clinic templates and the links to e-triage and pathways of care within DCN. Ideally there would be process consistency on development of clinic templates which would allow us to understand how effectively capacity is being used at present and for which pathway. It would also help to describe existing clinical activity and demand more accurately. Some of this work has been done as part of the process of introducing patient focused booking and e-triage but other areas for development are:

- looking to see if there is a way that we can identify activity pertaining to particular groups of patients or pathways of care,
- standardising recording of virtual clinics
- referrals from other specialties/ liaison activity
- telephone enquiries or telephone consultations.

In the process of joining up services around patients it would be interesting to consider administration processes in terms any communication with patients and the implications for joined up clinical care. If we were working more as a multidisciplinary team we would perhaps conceive of this as more of a joint assessment and joint triage/allocation process.

Some of the elements of the scheduled care improvement plan include standardisation of processes particularly around waiting times and outpatient services. As per comments in earlier sections, this blanket approach may not be as the equally valid for all pathways and patient groups so it is perhaps worth giving more thought to the elements of process consistency that we would wish to prioritise.

A specific issue for process consistency is ensuring we have processes to capture all patients in a pathway – so pathway leadership teams can retain and develop an overview of quality and the number of patients. This means that when a confirmed diagnosis /decision that a patient is appropriate for a pathway of care – there is notification/referral to the specialist nurses/pathway administration.

**What do we need to do?**

We need to make a start.

We need to record and use diagnoses of MS, epilepsy and functional symptoms.

We need to:
- standardise recording of virtual clinics
- record and review referrals from other specialties/ liaison activity
- telephone enquiries or telephone consultations.
2.24 Development of clinical communications using new media

Why is this in the plan?

As we’ve seen this was a priority from the stakeholder day and there are some small initiatives in place already, for example some consultants hold telephone clinics or schedule telephone appointments. There has been discussion about telephone advice for GPs, for example and an interest in learning from the stroke hotline.

The neurology service is introducing e-triage.

The nurse specialists are accessible to patients by phone and to other professionals.

We do know though that from other clinical areas that the clinical skills required by these different ways of communicating and undertaking clinical work differ from those used in traditional settings, not least requiring at the moment quite an entrepreneurial and determined approach to manage and use IT and technology.

We know that many clinicians feel that they prefer to meet and see the patient face-to-face, at least initially. In services like Lothian unscheduled care service which has been paperless and is fundamentally a telephone-based service at the front-end, we’ve learned that algorithm assessed triage is different from clinician assessment in triage and that some clinicians are more confident and more effective at telephone triage than others.

It’s not clear that there is a systematic approach to these developments in terms of training or research or general development. For that reason this area of clinical care would benefit from the similar attention and scrutiny that we would give to other clinical developments.

What do we need to do?

We need to aspire to have clinical leadership in place within services, not necessarily relying on general clinical leadership at Lothian level.

We need to actively offer and seek interest in such a role, having defined the role in terms of potential time commitment.

We need to review our research interests to see if there is potential to develop research and audit in this area.
2.25 Pathway and performance monitoring

Why is this in the plan?

We have agreed that we need clear and transparent pathways of care for specific conditions. Earlier sections of this document have identified which pathways we are focussing on initially and also the importance of these for neurology and neurosurgery as well as for other specialties and delivery challenges.

We are working through gaps in these pathways in terms of input from multiple disciplines, in line with our aspirations for multidisciplinary care.

To move a pathway from being a document which represents the theory of care into action, we need to be able to monitor, review and develop the pathway.

In particular, if we are arguing for shifts in resources to implement pathways we need to ensure that we deliver on the rationale and manage demand and capacity in each pathway effectively.

Putting in place these processes for monitoring should also help with the aim of achieving joint working and proactivity effortlessly – providing more routinely available data and avoiding the need for successions of data scrabbling or audits.

In terms of wider performance management, an integrated or joined up performance management framework might help us progress aspirations for a joint management team and a joined up approach to planning and resource allocation.

What do we need to do?

Mainly we need to bear this general aim in mind.

We need to agree minimum data sets and mechanisms for pathway monitoring across all sectors.

We need activity data on rehabilitation services

As per the sections on AHPs and psychology – we have no overall view of current activity.
2.26 E-health

Why is this in the plan?

Maximising existing IT systems in basic, simple but perhaps a bit clunky, ways to join up care is fundamental to making progress on pathways and knowing who we are looking after.

We have a broader vision for e-health:

**Vision** — to put in place an integrated e-health system which supports seamless, co-ordinated and integrated care for people with on-going neurological conditions in Lothian; to enable clinicians and patient administrators to work within a virtual practice/service across all sectors (primary care, community nursing, social care, neurology and neurological rehabilitation

Key principles of this system:

- Based on paperless records
- Requires consistent coding across the system
- Maximise the opportunities of the clinical portal
- Shifts the balance from medical care /doctor driven to reflect contribution of
  - multidisciplinary working in maintaining and enhancing functional status
- Should incorporate safety nets and alerts to avoid loss of follow up
- Should support responsive care to prevent crisis
- Supports self care
- Supports the collations of data for performance managing and research including patient outcomes
What do we need to do?

The main thing we need to do is to start using the functionality that is already in place (e.g. entering a diagnosis and using boxi reports to generate information which informs clinical care in practice)

We need to nudge forward to overcome motivational inertia – the too busy clinicians don’t use existing clunky functionality so the too busy e-health team don’t have the encouragement to prioritise the development of the system’s functionality because they’re not sure that these developments will be used in practice.

We need to share our knowledge, tips and work around and agree some standard approaches.

In relation to recording a diagnosis, pathway and performance monitoring, we need a mechanism for agreeing and building a standard/consistent data set and coding.

As with the issue of developing different media for communication and clinical care, we need to consider that the development of e-health is a fundamental service/clinical activity, not an add on which can be fully outsourced to a single system, e-health function. It would be great to have an e-health lead for neurological care – even on a temporary basis.
2.27 Networks of Excellence

The importance of joining up/integrating multidisciplinary services, for care of individuals and for planning and development is a fundamental theme of this report.

Taking a strong organisational approach to integration\textsuperscript{12} might mean designing our organisation around people with neurological conditions.

Whatever our approach to organisational design we also need to consider the opportunities offered by network models of working.

The Parkinson’s service and Parkinson’s UK have been championing the Parkinson’s Net Model, an innovative regional network introduced in the Netherlands. Evidence emerging from Parkinson’s Net\textsuperscript{13} shows that this has been effective in addressing many of the problems of development and access to appropriate expertise in distributed or fragmented systems where co-ordinated treatment focuses on suppression of symptoms with drugs and that referral to other disciplines for other forms of management and support – for example, physiotherapy, occupational therapy and speech and language therapy is “arbitrary” (Bloem et al 2014) and clinical staff, particularly AHPs, with expertise in Parkinson’s disease were hard to find\textsuperscript{14}.

Table 1 Types of integration

<table>
<thead>
<tr>
<th>Systemic</th>
<th>Coordinating legislation, policies, rules and regulatory frameworks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normative</td>
<td>Developing shared culture and values</td>
</tr>
<tr>
<td>Organizational</td>
<td>Coordinating structures and governance systems within and between organizations</td>
</tr>
<tr>
<td>Administrative</td>
<td>Aligning back office functions, budgets and financial systems</td>
</tr>
<tr>
<td>Informational</td>
<td>Developing clinical and managerial information systems</td>
</tr>
<tr>
<td>Clinical Coordinating</td>
<td>Patient care across clinical teams and organizations</td>
</tr>
</tbody>
</table>

\textsuperscript{12} Bloem, B.R. and Munneke, M. Revolutionising management of chronic disease: the ParkinsonNet approach. BMJ 2014 348:g1838 doi: 10.1136/bmj.g1838 (Published 19 March 2014)

\textsuperscript{13} Bloem et al also noted that interdisciplinary collaboration and communication between clinicians was inadequate although there was evidence that it was better amongst clinicians with higher caseloads of people with Parkinson’s disease. They noted that patients complained that they were not involved enough in decisions about their treatment and insufficient attention was paid to the quality of their lives.
What do we need to do?

We need to continue to work with Parkinson’s UK to move towards developing ParkinsonsNet model in Scotland.

We need to consider that similar network models for other neurological conditions would be of value, but also be mindful that multiple networks may not be feasible, that is that part of the success may be its uniqueness.

We need to note that networks such as this require to be resourced.

2.28 Delivering a different relationship with patients: choice and partnership

NHS Lothian Strategic Plan identifies the importance of delivering a different relationship with patients and the public and sets out a list of things that we know that patients want from their relationship with the NHS and many of these are themes throughout this plan. These include the value of the relational aspects of care found in individual consultations and team working around the patient, continuity of care, smooth transitions which require planning and co-ordination and that obvious inefficiencies are addressed.

In the course of the discussions of the Neurological Care Improvement Group and in the meeting with Neurological Voices we identified a range of current or “trending” themes and approaches to transformation. Some of these are listed in the foot note below\(^\text{15}\).

All of these approaches are important, valid and positive but taken together they present challenges: inaction as a consequence of trying to prioritise amongst them, failure to get maximum synergy or ineffectiveness as a consequence of diffusion of capacity and attention and “proliferation of initiatives”.

When we tried to outline some unifying principles which are “must do’s” whatever organisational arrangements, service configurations, populations segments or pathways we use for planning and delivery .we identified that at the core of health care delivery is the interaction and communication between individuals: patients, carers, families and communities and staff.

\(^{15}\) Person centred care: Person centred care : moving from “what’s the matter care/medicine to what matters to you?” Supporting self management/co-production Ensuring effective contributions from health care and social care (Integration) Developing integrated care pathways Management of long term conditions Effective risk stratification Management of complexity/multiple morbidity Focus on prevention Efficiency Effectiveness Quality Shifting the balance of care Population/resource segmentation (for example thinking about pathways for specific sectors of the population) Managing scheduled and unscheduled care
This plan therefore also recognises the fundamental importance of delivering a different relationship with patients and the public.

When we developed the generic integrated care pathway, this sought to address obvious inefficiencies and put in place the obvious elements of a pathway, but did not directly or explicitly consider the opportunities to deliver a different relationship with patients, families and carers.

We have now developed our thinking on some of the ways we could develop services, functions and pathways to deliver a different relationship, developing choice and partnership.

### What do we need to do?

We need to review pathways of care (or parts of pathways of care) to reasonably maximise patient choice – including mode of communication with clinicians and communication from our patient administration systems.

We need to review the Choice and Partnership Approach being considered by our Child and Adolescent Health Services and to see if there is anything that we can learn from this.

We need to ensure that all aspects of communication and pathways can support de-escalation of care and interventions.

We need to consider the development of a brief intervention for clinicians which promotes positive communication, person centred care and self management.

We need to recognise that services can inadvertently undermine self management, and develop actions to mitigate this.

We need to explore options for increasing patient choice and partnership are in line with our “service led“ efficiency and transformation aspirations.
Lothian Neurological Care Improvement Plan
2014 to 2017

Part Three
Integrated Care Pathways

3.1 Epilepsy

Why is this in the plan?

Based on General Practice QOF register for epilepsy for 2012/13 there are 5,924 people with a diagnosis of epilepsy in Lothian.

NHS Lothian Epilepsy service estimates 6,000 to 7,000 – of which 30 to 35% are best dealt with by specialist service (2,100 to 2,450).

The figure for Lothian is based on 0.7% of total Lothian population (prevalence estimate from ISD based on national QOF data is 5,942).

Epilepsy is the third highest reason for a new outpatient appointment (approximately 14%).

Epilepsy is more common in people with a learning disability than in the general population.

- About 30% of people (nearly one in three) who have a mild to moderate learning disability also have epilepsy.
- The more severe the learning disability, the more likely that the person will also have epilepsy.
- Around 20% of people (one in five) with epilepsy also have a learning disability.

The learning disability (LD) service estimate around 500 people on their total case load with active epilepsy.

Seizures account for 2 to 3% of emergency department attenders.

EEG for first seizure – epilepsy service estimates five to six patients every two weeks

The March 2013 IRF analysis based on the financial year 2012-2011 used ICD 10 coding of neurological conditions, including epilepsy, to identify patients. This showed that patients with epilepsy (566) account for the highest total health and social care costs £11.7M, with costs in the IRF indicating a balance across health and social care of £5.8M per agency.

A further analysis of IRF identifying patients through coding of epilepsy as a long term condition identified, for financial year 2010-2011, 2535 people receiving 21,504 episodes (records) of care and 17,066 records of health care.
The total health care costs of Lothian patients aged over 15 for 2010/2011 was £5,108,887\textsuperscript{16}. Excluding people the LD specialty from the analysis, 21 cases incurred NHS costs over £50K accounting for 22.2\% (£1,825,611).

The social care costs for people aged 14-64 were £12,108,586, with residential care for 144 people being the category with highest cost. Of these, 81 people were categorised as LD, 29 with physical disability and seven vulnerable people.

A revised SIGN guideline (Scottish Intercollegiate Guidelines Network) for diagnosis and management of epilepsy in adults is expected in the near future.

The GMS contract agreement for 2014/15 moved the maintenance of disease registers from the QOF framework to a core function, which includes the register for people with epilepsy.

\textsuperscript{16}£1.309,574 of the NHS cost was accounted for by a small number of individuals with Profound and Multiple Learning Disability in an NHS continuing care unit
What do we need to do?

Develop epilepsy care pathway in line with generic care pathway (specify priorities)

Include record socioeconomic status and social vulnerability

Undertake epilepsy specific needs assessment including demand and capacity requirements – to incorporate first seizure clinics/development of 24/7 rapid access and to consider the shift of existing capacity into specialist epilepsy provision and demand and capacity for neuropsychological and psychological assessments and interventions

Ensure everyone with epilepsy or possible epilepsy is referred to the epilepsy specialist service and is seen an a specialist epilepsy clinic

Review work on frequent attenders at emergency department, outpatients and admissions (all outpatients and admissions)

Review interface with primary care in line with risk stratification undertaken as part of implementation of care pathway: specifically
  - GPs recording people with refractory epilepsy on their chronic disease register (failed on two or more epileptic drugs)
  - GPs recording people with epilepsy and LD on their epilepsy and LD registers
  - Review of epilepsy related prescribing
  - Confirmation of review of seizures – develop a wholesome attitude to making sure seizures are well controlled

Ensure GMS data is shared with epilepsy service and consider shared review of a sample of patients

Risk stratification (expect approximately 30-35% of patients to be considered at risk) to be under care and review by specialist epilepsy service

Further develop interface with LD epilepsy service in relation to Joint clinics

People with LD and epilepsy attending emergency department, admitted to hospital

Development of telemetry - requirements for transition to new DCN
3.2 Headaches

Headache, including migraine, is a common problem and is in the top ten causes of disability. It is usually self-managed but has been estimated to account for 44 consultations per 1,000 people in primary care. Although GPs refer only 2-3% of patients consulting for headaches, this condition accounts for up to one third of new specialist neurology appointments in the UK.  

- Headache affects 95% of people in their life-time
- Headache affects 75% of people in any one year
- One in 10 people have migraine
- One in 30 people have headache more often than not, for six months or more
- At least 90% of patients seen in a neurology clinic with headache will have migraine, tension type headache, or a chronic daily headache syndrome
- Sinister causes of headache are rare, perhaps 0.1% of all headaches in primary care

A study which looked at GP referral patterns found that over a one year period the majority of GPs (63%) made no referrals of people with headache, 33% made one or two referrals and 4% made three or more referrals.

Moreover, those people with headaches who are referred are not more severely affected are experiencing greater disability, raising questions about the reasons and needs for specialist referral. Other research has shown that patient anxiety and pressure for referral are important where GPs are not able to convince patients that there is no organic cause and the patient is a frequent consulter and their headache was of considerable duration. GPs “willingness to refer” depended on clinical confidence, ability to tolerate uncertainty and local availability of services, including availability of alternatives to neurology.

Why is this in the plan?

Headaches and migraine account for considerable use of capacity in both primary and secondary care as well as considerable disability for a number of patients. Much of this activity and use of service capacity may be ineffective.

Many analyses have pointed out that small changes in referral patterns from GPs can have a major effect on capacity in neurology – GPs transferring only 1% of headache referrals to neurologists will double the demand for new appointments for headache. It should also be pointed out however that a similar logic applies in relation to general practice; a small increase in the numbers of patients who manage their headaches themselves would make a major difference to capacity in general practice.

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18 Davenport R Headache Neurology in Practice 2008 8 335 to 343
What have we done so far?

NHS Lothian agreed that, in the context outlined above, headaches should be one of three clinical areas for focus in relation to the “referral management” area of the GMS (GP) contract.

As part of this work

a) the RefHelp guidelines were reviewed and a protocol for referral introduced, this included:

- a reminder that GPs have direct access to CT scan, though there would still be an issue about the appropriateness of using this

- prompts for ensuring that key treatments for acute migraine have been tried, that key preventative treatment for migraine have been tried and that medication overuse headache has been considered (tried stopping regular analgesia)

b) educational sessions on headache and the RefHelp guidelines were held with GPs across Lothian

c) The Neurology Department carried out a before and after audit of referrals for headache in Lothian

d) the results of the audit have been reviewed and shared at a further educational session with GPs

DCN have appointed a consultant neurologist with a specific interest in headaches and with responsibility for the specialist headache clinic.
What do we need to do?

We need to continue to work on pathways for people with headache, including pathways in primary care, in general neurology and through to specialist headache clinics.

We need to keep in mind that only a very small number within the very large number of people presenting to primary care are referred to specialist neurology. We need to focus on shifting the balance of care from health care to self management and not simply trying to shift the balance from secondary care to primary care.

We need to evaluate options and audit the development of interventions such as optical nerve block and ensure that developments are clearly represented and understood in the context of an integrated care pathway.

We need to continue a dialogue with GPs and develop an on-going communication and education programme.

As is the case for other pathways we could formally define a clinical lead for headache and a leadership team which could include a general practitioner with a special interest in headache.

We need to develop a business case for a headache specialist nurse to support and carry out patient follow-ups and liaise with general practitioners.

We need to develop a robust multidisciplinary approach to the management of patients with headache, including opportunities for behavioural and psychological approaches.

We need to develop ways of communicating with patients which are appropriately reassuring and educational, including developing patient information leaflets.

We need to consider opportunities to develop and support self management.

3.3 Functional Symptoms

Functional neurological symptoms are symptoms such as blackouts and paralysis that are genuine but not due to a neurological disease. They include dissociative (non-epileptic) attacks, functional limb weakness/movement disorder, sensory, visual, speech and cognitive symptoms.

Why is this in the plan?

They are the second commonest reason for a neurology outpatient visit in Scotland and are a cause of severe and complex disability.
The Healthcare Improvement Scotland programme of review and improvement recognised the lack of awareness of the impact of functional neurological symptoms and noted that inconsistent care required to be addressed.

The Health Care Improvement Scotland Standards for Neurological care include:

Criterion 4.4a
The neurology service has access to an integrated neuropsychology and neuropsychiatry service providing a diagnostic and treatment service for patients with neurological symptoms unexplained by disease.

NHS Lothian currently has an integrated diagnostic service but no defined service for treatment.

What have we done?

We have developed an evidence based care pathway for people with functional symptoms (Appendix 6).

We have begun a programme of education and training, running a well attended half-day workshop on the diagnosis and multidisciplinary management of neurological functional symptoms.

We have prepared business case for implementation of an evidence based care pathway for people with functional symptoms which includes an economic analysis which provides evidence for cost effectiveness (Appendix 8).

We have identified the impact of not implementing this pathway as below:

- NHS would be open to criticism of being discriminatory on the basis of diagnosis in respect of this group of patients whose symptoms, experience of distress and disability are comparable with those of patients with stroke and other neurological conditions.

- Patients would not consistently access evidence based treatments which would improve their health and are in line with national quality standards.

- Costs in further outpatient appointments within neurology and in other specialties continue to accrue estimated at £149,800 in 2012 and inpatient stays (estimated at £690,000) will continue to accrue when a significant proportion of these costs would be avoidable if the evidence based pathway was implemented.

- Research evidence indicates that in the 12 months after a neurology outpatient appointment the total number of further outpatient appointments were as follows: 328 general medicine, 600 general surgery, other specialties 300, and rehabilitation medicine 8.
• Research evidence indicates that one in ten people in 12 months with functional symptoms receiving (no) treatment as usual were subsequently admitted as a neurology in-patient and 115 per 1000 were admitted to other specialties with general medicine being the most frequent specialty of admission (total of 450 in-patient days).

• Research trials have shown a 50% reduction of further referrals and admissions following the implementation of an evidence-based pathway.

• Analysis shows that return on initial investment of two therapist posts would be achieved with a 25% reduction in further referrals.

What do we need to do?

We need to make arrangements for pathway leadership and ensure that these responsibilities are formalised within appropriate job plan/PDPR (Personal Development and Performance Review) and objectives.

We need to establish multidisciplinary team working to support people with functional neurological problems.

We need to confirm arrangements for pathway monitoring.

We need to identify resources for two WTE Band 6 therapists; allocated to enable the implementation of step 2 of the pathway, in the context of other pressures and demands.

We need to ensure that the multidisciplinary team has some capacity and an implementation plan for awareness raising and education.

We need to confirm the input from specialist rehabilitation services in respect of engagement in the integrated care pathway and support for step 3 of the pathway.

We need to confirm the capacity available (or gap to be addressed) in relation to neuropsychology input for step 3.

3.4 Parkinson’s Disease

See also Part 3, section 2.6 on Parkinson’s Services

The majority of people with Parkinson’s are referred untreated to the relevant Service within NHS Lothian. The Lothian Parkinson’s Service Advisory Group (LPSAG) has developed Ref Help guidelines for GPs on the initial referral pathway (attached). This went ‘live’ in 2014.
We need to improve early detection and recognition of people with Parkinson’s in Lothian. In order to achieve this, it is vital that we educate those in the community: doctors, nurses and AHPs. This can be partly achieved through direct education such as the LPSAG Forum and use of indirect systems such as the online LearnPro module.

Detection rates of new cases and those lost to follow up will only improve significantly, however, if there is:

- The development of a database of all people with Parkinson’s in Lothian that is maintained and updated,
- Easy and regular access GP computerised data across Lothian to ensure that information on anyone with a coded diagnosis of parkinsonism and related disorders is captured.
- Coding of all patients with a diagnosis on the hospital TRAK system. At present, only those with an inpatient episode have a coded list of diagnoses. Since mid-2013, the Parkinson’s Nurse Team and certain specialists have been entering diagnostic codes for any outpatient with Parkinson’s. This should eventually allow immediate identification of any people with Parkinson’s who present to hospital services.

There will need to be funded administrative support to develop and maintain a database.

Whilst we develop integrated pathways of care for Parkinson’s as a specific condition, the general models and issues could apply to other conditions.

**Network of Multidisciplinary Care**

In the Netherlands, ParkinsonNet.info has revolutionised the management of Parkinson’s by standardising and integrating the delivery of care to people with Parkinson’s across that country. ParkinsonNet is a network of multidisciplinary teams who share information, training and outcomes, ensuring that people with Parkinson’s get the same standard and level of care wherever they live. This has resulted in a 55% reduction in hip fractures in people with Parkinson’s, greater management of patients within the community setting including independent living at home, improved quality of life, and a reduction in overall health costs.

In 2014, Dr Conor Maguire, Chair of LPSAG met with the Director of ParkinsonNet and with Parkinson’s UK to explore piloting such a model in Lothian. In preparation for this, Dr Maguire submitted an application to the Scottish Government SCIPP (Scottish Collaborative Innovation Partnership Process for future care outside hospital in Scotland) seeking approval and backing for the appointment of a Specialist Parkinson’s Physiotherapist to co-ordinate the development of such a multidisciplinary network which will reduce geographical inequalities and standardise multidisciplinary care across Lothian. This has passed the first stage of the process and is ongoing.
Ongoing Care

Once any new patient has been seen and assessed by a specialist, and a diagnosis made, that patients should be automatically referred on / offered the opportunity to be reviewed by:

- The Parkinson’s Nurse Specialist team
- The therapist-led Edinburgh Parkinson’s Assessment Clinic (EPAC)

All people with a new diagnosis of Parkinson’s should be offered on-going follow up / access to a specialist. The minimal follow-up should be annual by a specialist consultant, with in between ad hoc by PDNS.

All people with Parkinson’s should be given information about Parkinson’s UK, and the support and education offered by the Edinburgh Branch of Parkinson’s UK.

NHS Lothian needs to continue to support the LPSAG to ensure that this stakeholder group can help to develop the services for people with Parkinson’s in Lothian and provide ongoing support and education for those working with people with Parkinson’s. This will require administrative support.

General Practitioners in Lothian need to be provided with information, education and support on what aspects of care for people with Parkinson’s that they can provide well without having to access Parkinson’s specific services.

Access to Allied Health Professional Services

As outlined below, the EPAC now offers all patients given a new diagnosis of parkinsonism access to a once-off assessment by a physiotherapist, speech and language therapist, and occupational therapist. The aim of this clinic is to provide education and information to assist patients in self-management.

After patients have had their initial assessment, there is still, presently, no standardised pathway of care to therapy services. The development of a Multidisciplinary Network, as outlined above would help to achieve this.

Physiotherapy:
The Lothian physiotherapist service has identified the need for

- Specific staff training in Parkinson’s
- A dedicated Parkinson’s physiotherapy intranet page to aid communication between professionals
- A system that allows regular review of patient education throughout the patient’s journey
- A system whereby staff competencies in Parkinson’s is reviewed regularly
- The evaluation of community exercise programmes for Parkinson’s

Much of the above would be achieved through the appointment of a specialist Parkinson’s physiotherapist for Lothian. European guidelines on the use of
physiotherapy in Parkinson’s are due to be published in 2014 and these guidelines will also help guide how services will develop in Lothian.

**Speech and Language Therapy (SLT):**
The speech and language therapists in Lothian have identified the opportunity to develop a standardised approach to group work for solution-focussed brief therapy to support self management and active therapy tasks similar to those used in the Lee Silvermann Voice Training.

Other SLT plans include:
- To review the equipment available to SLT staff/patients in Lothian University Hospital Trust
- To develop a training strategy – Parkinson’s resource pack on SLT shared drive
- To develop a SLT study session, a competency framework, and consider steps which will increase the service’s ability to offer the Lee Silvermann Voice Training
- To consider how the service may provided early dysphagia rehabilitation
- To develop and act on user feedback.

**Occupational Therapy:**
There is a positive perceived impact of occupational therapy in preventing future complications in people with Parkinson’s. This includes early provision of aids to assist with independent living and reduction of falls through safe transfer practice. However, it is acknowledged that a large-scale trial is required to outline the specific benefits of OT in people with Parkinson’s.

**Other disciplines:**
**Over 60% of patients** with Parkinson’s report one or more neuro-psychiatric symptoms at some point in the course of their illness. In Lothian, there needs to be more joint psychiatry/Parkinson’s specialist clinics to provide expert management and care to these patients. There also needs to be adequate and equal provision of psychology services across Lothian.

Fifteen percent of people with Parkinson’s are classed as being in the palliative stage of the illness at any one time. The palliative stage of Parkinson’s may last up to two years, and yet there is no robust palliative care system in place for such patients in Lothian. This needs to be addressed through interactive working between Parkinson’s specialists and palliative care teams in Lothian.

**Access to Clinical Trials and Research**
All people with Parkinson’s should have the opportunity to participate in Clinical Trials and Research relevant to their condition. The LPSAG is very keen that NHS Lothian provides support and time allowance to facilitate healthcare staff working with people with Parkinson’s to achieve this.

LPSAG is also very keen to establish a Brain Bank for Parkinson’s in Lothian.
3.5 Multiple Sclerosis

Multiple sclerosis (MS) is the most common disabling neurological disease in young adults.

It is typically diagnosed between ages 20 and 40 but it can affect younger and older people too. Roughly three times as many women have MS as men. MS affects everyone differently. There are different types of MS\(^{20}\). People with the same type of MS won’t necessarily experience the same symptoms in the same way. Diagnosis is complex and often a lengthy uncertain process.

Common symptoms include upper and lower extremity disabilities, visual disturbances, balance and coordination problems, spasticity, altered sensation, abnormal speech, swallowing disorders, fatigue, bladder and bowel problems, sexual dysfunction, and cognitive and emotional disturbances. Symptom management, along with disease modification treatments, are complex. The psychological and social impact of the disease on patients and families is substantial.

Despite the progress in diagnosis, understanding of the pathomechanisms, and treatment, half of the patients with multiple sclerosis are forced to leave employment after ten years of illness, owing to fatigue and neuropsychological disturbances.

MS imposes a significant economic burden on those suffering from the disease, on their families and on society as a whole. A recent international literature review identified six main cost areas associated with MS (accounting for 75% of the cost): informal care, disease modifying drugs, professional home care, hospitalisations, cost of other prescriptions, and early retirement and loss of employment. Of these, early retirement and loss of employment are the most significant factors\(^{21}\).

**Why is this in the plan?**

There are around 2000 people with MS in Lothian.

MS is the fourth most frequent reason for an out-patient appointment.

Analysis of IRF data for 2010-2011 identified 450 people with a diagnosis of MS and a total spend across health and social care of £6.8M (£2.9M NHS and £3.9M social care).

\(^{20}\) Relapsing remitting MS (around 85% of people diagnosed with this type of MS), secondary progressive MS – as sustained build-up of disability over relapses without full recovery. Most people (65%) with relapsing remitting MS will go on to develop secondary progressive MS 15 years after diagnosis. Primary progressive MS (10-15% of people diagnosed with MS and usually diagnosis in people in their forties and fifties – with equal numbers of men and women.)

\(^{21}\) Global Economic Impact of Multiple Sclerosis May 2010 Literature Review Prepared for Multiple Sclerosis International Federation London, United Kingdom
There is no integrated care pathway for people with MS.

Though the lead consultant and MS Specialist Nurses at DCN hold a database of people with MS, this is not available to specialists in rehabilitation and wider teams and networks involved in the care of people with MS and has not be used as a basis for planning multidisciplinary team working across sectors.

**What have we done?**

We have developed a draft integrated care pathway for the care of people with MS.

We have participated in a workshop held in partnership with the Stroke Association and the Multiple Sclerosis Society on employment of people with these conditions.

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**What do we need to do?**

Endorse draft MS pathways

Undertake MS specific needs assessment including demand and capacity requirements across DCN and neurorehabilitation

Develop Electronic Patient Record for people with MS or adapt Community TRAK records

Seek to establish a single point of contact across DCN and neurorehabilitation for people with MS

Clarify social care pathways for people with MS

Agree risk stratification to identify complex cases requiring regular MDT review

Introduce patient centred outcomes across DCN and Rehabilitation

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**3.6 Motor Neurone Disease**

Motor Neurone Disease (MND) is a rare progressive disease that damages the motor neurones, or nerves, in the brain and spinal cord. MND can affect how you walk, talk, eat, drink and breathe. It affects everyone differently.

Although there is currently no cure for MND, symptoms can be managed to help you achieve the best possible quality of life.
Services for people with MND are linked on a regional basis covering NHS Lothian, NHS Borders, NHS Forth Valley and NHS Fife. There are around 120 people with MND across these areas.

The MND Specialist Nursing Service covers all these health board areas. Everyone who is diagnosed with MND is referred to this service and the service aims to contact everyone within three working days of referral after a new diagnosis. The Specialist Nurses work as part of multidisciplinary teams in each of the health board areas. Patients are seen in multidisciplinary or nurse led clinics or through the provision of home visits for people who are physically unable to travel. The specialist nursing service provides coordination and continuity of care for people with MND, aiming to contact people at minimum every three months unless patients decide this is not necessary. Additionally patients can get in contact the service at any time.

The services work closely with the University of Edinburgh Centre for Regenerative Neurology, the Anne Rowling Clinic and the Euan MacDonald Centre for research into MND and in Lothian the Specialist MND Clinics are held at the Anne Rowling Clinic on the Royal Infirmary of Edinburgh site.

What do we need to do?

Review of generic care pathway as applied to MND

Review of existing pathways for diagnosis, symptom management and anticipatory and palliative care

Ensure access to nutritional support, enteral feeding and respiratory support on an “as required” basis.

Review all emergencies and admissions - consider on-call system for specialist nurse

Maximise fortnightly clinic, including move to virtual clinics using telemedicine and input from community services

Ensure that patients diagnosed with MND have rapid access to social care in all local authority areas including access to equipment and adaptations
3.7 ME-CFS

ME-CFS are fluctuating conditions which produce effects on a variety of body systems. The experience of ME-CFS, and duration, varies between individuals and over time. It is characterised by persistent and fluctuating symptoms of fatigue, pain and loss of endurance to normal activities associated with conspicuous deterioration after exercise.

A UK wide survey carried out by Action for ME of people with ME-CFS showed that people with ME-CFS experience considerable disability (87% of people in this survey had stopped or reduced work and 92% had reduced social contact). The condition and impact can be considered ‘invisible’ and as is the case with other ‘invisible’ conditions, this brings difficulties in terms of establishing the legitimacy of the experience and managing the perceptions of others.

Some people see significant improvements or recover in less than two years, whereas others have a series of relapses, or remain ill for many years.

There are estimated to be between 1696-3392 adults over 18 with ME-CFS in Lothian (reflecting an estimated prevalence of 0.2% to 0.4%)\(^{22}\).

The Scottish Good Practice Statement on ME-CFS 2010 recognises that ME-CFS is associated with altered neural functioning and causes significant and in some cases, profound disability. As such it places a substantial burden on people with the illness, their families and carers, often for many years, and on society.

Diagnosis for ME-CFS is clinical, (no biomarkers have been identified), made on the basis of detailed medical history, with diagnostic tests ruling out other conditions. Research is continuing into the causes and effective treatments. In this context, there has been much debate within ME-CFS patient groups and between medical specialties on treatment options.

The criteria for diagnosis for this illness have recently changed to symptoms persisting for at least four months (instead of 6).

There is a code for CFS but it is not always used. Patients presenting with symptoms compatible with a label of ME-CFS are coded to a variety of ICD codes, which means that it is difficult to review, understand and audit care for people with ME-CFS and hence to improve the care pathways. It is likely that people with ME-CFS use a range of services without positive and effective outcomes, with the process itself being distressing and unhelpful for patients.

The World Health Organisation (WHO) has classified Benign Myalgic Encephalomyelitis (ME), including post viral syndrome under disorders of the nervous system (neurological diseases) ICD 10 G93.3.

\(^{22}\) Based on the ScotPHN Needs Assessment estimates, itself drawn from estimated provided through the Regional Infectious Disease Unit (RIDU) in Lothian (compared with the estimate included in the infographic from neuro numbers of 3396. Used the prevalence but not the original figures in CS document.
NHS Lothian Services for ME-CFS Patients

Lothian has an explicit pathway for patients presenting with prolonged unexplained fatigue/ME-CFS which was based on the recommendations from the ‘Believe in ME Report’ and the Scottish Good Practice Statement on ME-CFS

The majority of patients will be diagnosed and managed in primary care.

The Regional Infectious Diseases Unit (RIDU) has historically seen ME-CFS patients, primarily to exclude alternative causes of illness, both infectious and non-infectious. In practice, alternative diagnoses are very rare in the cohort of patients referred to RIDU, and staff at RIDU have developed expertise in assessment of fatigue of unknown cause and the provision of advice to patients. This function of RIDU has evolved without direct resources for a ME-CFS service.

In Lothian, support services for people with ME-CFS follow ‘a 1-2 Tiered’ services approach similar to those described in the ScotPHN National Needs Assessment.

The provision of two years of funding by the Scottish Government has allowed NHS Lothian to provide this Pilot Rehabilitation Service for people with ME-CFS. The service is an out-patient, adult service (age 18 and over) and began taking referrals on the 8 November 2012. Referrals into the service have to come via the GP or a RIDU consultant.

NHS Lothian estimates 120 individuals can be supported per year by the rehabilitation service. It is expected that 75% of individuals accessing the service should expect an improvement in their condition as a result of intervention.

Why is this in the plan?

ME-CFS is a significant cause of complex disability and suffering in young adults.

As indicated above, the World Health Organisation classification and the Scottish Good Practice statement recognise the contribution of neural functioning to the condition. The Neurological Alliance for Scotland includes organizations supporting people with ME-CFS as does the Neurological Voices Programme. The current Scotland National Neurological Advisory Group are also considering ME-CFS in their programme of work.

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23 Patients are seen individually and many may see both a physiotherapist and a psychologist during the course of their therapy. A collaborative, self-management lifestyle programme with an individualised patient-centred menu (from a number of topics offered over 10 sessions) has therefore been devised. The service will then also offer a 3 month follow-up session.

Service management responsibility for the Pilot ME-CFS Rehabilitation Service and the Chronic Pain Service are at AAH. Professional supervision to the psychology team is provided by the NHS Lothian’s Head of Psychology Service for Physical Health and Neuropsychology.
In terms of rehabilitation and on-going support, there is the potential for people with ME-CFS to benefit from skills in neuro-rehabilitation and pain management.

What do we need to do?

We need to confirm clinical leadership for the ME-CFS pathway

We need to consider the findings from the evaluation of the ME-CFS Rehabilitation Service in the context of wider research evidence

We need to learn from developments of care and services for people with ME-CFS in other areas

We need to consider how we could improve routine monitoring of care for people with suspect of diagnosed ME-CFS with a view to understanding if we could improve the process of diagnosis (in terms of patient experience and cost effectiveness) and reduce the time taken to get a diagnosis.

3.8 Huntington’s

Why is this in the plan?

Huntington’s Disease is a complex progressive neurological condition.

It is an inherited disease of the brain that damages certain brain cells\(^{24}\) causing deterioration and gradual loss of function. This can affect movement, cognition (perception, awareness, thinking, judgement) and behaviour.

Early symptoms can include personality changes, mood swings and unusual behaviour, although these are often overlooked and attributed to something else. People with Huntington’s can exhibit challenging and forensic behaviour. The effect on families is devastating and attempting to manage need across the fragmentation of services adds an additional burden.

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\(^{24}\) In the majority of cases, Huntington’s disease is caused by an inherited faulty gene. However, in around 3% of cases there is no family history of the disease.
The previous plan underpinning the work of the Physical and Complex Disability Strategy Board began work on pathways of care for people with Huntington's, working closely with the Scottish Huntington's Association (SHA) and securing funding for an additional Huntington's specialist nurse.

NHS Lothian has no specific service or pathway of care for people with Huntington's. There is no lead consultant for Huntington's. There are no formal processes for regular multidisciplinary team review. All of these elements are currently being developed in partnership with Scottish Huntington’s Association (SHA) and a collaborative approach with the Lothian local authorities.

The SHA Huntington’s specialist nurses are the main co-ordinators of care for people. They are based in the Department of Clinical Genetics at the Western General Hospital.

As a consequence of being based here, the specialist nurses use the clinical genetics IT systems which as yet does not interface with TRAK.
The Huntington’s Disease Specialists triage a HD Clinic at Clinical Genetics Department WGH on a two monthly basis for medication and mental state reviews. The clinic is led by Dr Wong Old Age Consultant Psychiatrist who has a small sessional commitment work with people with Huntington’s.

There is some input from the Lanfine and Charles Bell rehabilitation services, and occasionally from in-patients at the REH.

Despite Huntington’s being a progressive and complex condition, requiring ongoing multidisciplinary and multiagency working, the Huntington’s specialist nurses are the sole point of continuity for people with Huntington’s and they are reliant on “people who become specialists because we keep referring to them” and people helping “out of kindness”.

The specialist nurses require to access a range of sector based general services (which operate on referral and discharge models) rather than being able to access a continuing multidisciplinary team with an open case file and formal care plan. General Practices and local teams do not know people well as relationship building is problematic given the nature of the disease.

We know that when people with Huntington’s are admitted to hospital for acute illness (which may be incidental), co-ordination of their care is problematic, management of their behaviour is problematic and discharge is problematic (if they cannot be discharged home). We know that finding appropriate care home or supported accommodation placements in Lothian is problematic and this leads to further delays in discharge from acute and rehabilitation/mental health settings.

We know that there is no Lothian-wide coordination of social care (residential placements) or complex health and social care for people with Huntington’s.

We know that the stress on carers is immense and it is difficult to access respite care.

We know that when people reach a point of deterioration or transition of care which requires a capacity assessment and consideration of guardianship or vulnerability, that accessing a timely capacity assessment from someone who knows the client or is familiar with impact of Huntington’s is problematic.

We know that, despite the complexity of Huntington’s, on-going multidisciplinary care planning or use of approaches such as the Care Programme Approach for managing complexity and risk, are not in place.

What have we done?

The SHA, working with families and carers, developed a care pathway and identified gaps in the pathway. We used this work, along with the generic care pathway, to review current NHS services and identify key priorities.

We have initiated the process of seeking to identify a lead consultant.

We also worked with SHA to anonymously analyse IRF data of people with Huntington’s.
We have initiated meetings with the other neurological specialist nurses to share expertise and approaches.

We have used the SHA database to estimate the number of residential (complex) placements required for people with Huntington’s.

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**What do we need to do?**

We need to identify a lead consultant for Huntington’s

We need to develop our e-health system in order that the Lead Consultant and Specialist Nurses can be notified when someone with Huntington’s is admitted to hospital.

We need to build a (virtual) multidisciplinary team around the lead consultant and Huntington’s Specialist Nurses which provides on-going care and care planning.

We need to develop a mechanism for timely and expert assessment of capacity and vulnerability for people with Huntington’s.

We need to encourage the development of a Lothian wide social care response for people with Huntington’s.

We need to seek to develop local residential capacity and intensive outreach capacity for people with Huntington’s.

We need to consider the development of a Care Programme Approach for patients with complex and high level of need and develop clear links to forensic expertise.

We need to develop an administrative and co-ordination centre for NHS services

We need to develop our capacity to support carers

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**Summary – Huntington’s Nursing Home/Care Home Placements**

Total of placements =41, over 10 years
18 current placements, 4 pending placements and 19 finished placements
Of the “finished” placements, for 9 of these information on length of placement wasn’t known. For the 10 placements where there was information on start and finish date this was an average of 28 months, but with wide range from 7 to 90 months.

For current placements, the length of placement for three of these was not known. For the 14 placements where length of placement is known,, the average is 25 months, but again there is a wide range from 3 months to 56 months.
21 people were male with 20 female.
Average age of people currently in placements is 49 years.
12 of the current placements are out of Lothian.
3.9 Head/Brain injury

Traumatic brain injury (TBI) is the leading cause of severe disability in working age adults in Scotland.

Brain injuries can produce a complex pattern of disability in physical, cognitive and emotional domains. Complications in the form of epilepsy, endocrine disruption, incontinence and movement disorders are commonplace. For families the real tragedy is personality change which is an almost inevitable consequence.

Services for people with head and brain injury have been known to be patchy, with information on epidemiology and service provision for planning limited. A National MCN for Acquired Brain Injury (SABIN) was implemented in 2006.

It is estimated that around 6,366 adults in Lothian present to A and E with head injury (around 17 per day).

Around 186 people in Lothian per annum will have severe traumatic brain injury requiring neurosurgical admission of whom 38% (70) will die or be in a vegetative state, 29% will have severe disability (54).

There are an estimated 2,784 admissions for traumatic brain injury per year, 2,598 of these moderate TBI for observations.

Across Scotland, the majority of admitted patients are managed in general or orthopaedic surgical units and thus care is likely to be more variable.

Many of the people with moderate to severe brain injury would benefit from comprehensive assessment and early intervention to achieve costs savings in relation to avoidable hospital admissions, reduced length of stay, reducing the costs of long term care and returning or sustaining people in employment.

Around 2,000 people who have had a brain injury will be living with long term problems, with around 212 people per year acquiring a moderate to severe brain injury.

Implementation of a range of SIGN guidelines and SABIN recommendations would support improvements in cost effectiveness of care, but it is not clear whether NHS Lothian meets these guidelines/recommendations or not.

Why is this in the plan?

The planning for the new DCN makes assumptions about the role/numbers of people with head/brain injury requiring neurosurgical intervention and has noted the importance of pathways of care across NHS Lothian for people with head and brain injury across Lothian.

Patients with moderate to severe brain injury admitted for observation would potentially benefit from medical and multidisciplinary neurological assessment
and early intervention and there is a requirement to consider the implementation of a pathway/model of care for these people.

There are concerns that the move of DCN to RIE could mean that there is inappropriate demand on neurosurgery and neurology for assessment of head/brain injury if clear pathways and protocols are not in place.

The planning for the REH/AAH reprovision includes provision of the (national) head and brain injury specialist rehabilitation units, recognising that neurorehabilitation services have an important role in support for people with brain injury.

What have we done?

We have recognised the importance of developing a pathway for head/brain injury and included this in the planning work for DCN.

What do we need to do?

We need to review our model of care for moderate to severe brain injury in line with SABIN proposals and the issues identified\(^1\).

We need to establish systems of recording information on head/brain injury patients which allow us to plan, monitor and improve our care.

We need to identify people with moderate/severe brain injury who would benefit from assessment, early intervention, follow up, review or on-going support and develop multidisciplinary capacity to deliver this.

We need to develop NHS and social care capacity to provide care and support for people with cognitive and behavioural problems including people with brain injury.
3.10 Stroke

Stroke is the third largest cause of death and the burden of morbidity of stroke is substantial.

Estimates for Lothian are that there are 1,698 first or recurrent strokes per annum. In addition to this there are 340 people experience transient ischaemic attack (TIA) and a further 6,112 people living with stroke (though the GMS QOF prevalence data for 12/13 shows that there were 15,907 people on the stroke TIA register).

Stroke is estimated to account for 10% of emergency admissions to hospital.

Around 30% of people assessed for suspected stroke but not confirmed as having a stroke would benefit from a neurological assessment.

Why is this in the plan?

There are important interfaces between neurosurgery, neurology and stroke medicine which need to be reviewed.

Neurological rehabilitation services provide rehabilitation for people who have had a stroke, that is the neurorehabilitation capacity (such as neurophysiotherapy) available, requires to provide rehabilitation for people with stroke as well as other neurological conditions. In order to understand and manage the demand on neurorehabilitation services in relation to the neurological conditions and pathways which are the focus of this plan, we need to understand the overall demand on services/key clinicians.

NHS Lothian has begun a review of the configuration of stroke services.

The proposal for the acute area of DCN includes capacity for all acute stroke patients admitted to the RIE for assessment or treatment (thrombolysis) before transfer to stroke unit.

What do we need to do?

We need to ensure that there is co-ordination between developing plans for stroke services and the acute area of DCN.
3.11 Dietetics

Neurological conditions can be associated with significant problems with eating and nutritional status.

People with neurological conditions are at risk of becoming undernourished as a result of increased protein and energy requirements and difficulties eating and drinking. Early nutritional input may improve length and quality of life and preserve physical strength for rehabilitation.

The Lothian Dietetic Service as a whole comprises only 80 whole time equivalent posts (comprising of 135 staff). With this limited specialist resource, two of the main functions of the service are:

- to prioritise the use of this limited resource carefully using a tiered model of provision and
- to develop the capacity of staff and other agencies to provide the majority of care in lower tiers of need, and for these staff and agencies to support community and self management approaches.

The top three problems faced by people supported by the dietetic service overall are malnutrition, diabetes and obesity. Whilst neurological conditions can bring specific and complex complications of eating and nutrition, people with neurological problems also experience the problems affecting the wider population.

All patients admitted to hospital are screened for malnutrition and risk of malnutrition using the Malnutrition Universal Screening Tool (MUST) and those at risk are referred to the dietician for nutritional support. At present the tool is not used routinely in an outpatient setting.

The aims of nutritional management in neurology and neurosurgical patients are to:

- Achieve and maintain an ideal body weight
- Reduce muscle wasting
- Meet daily requirements of all nutrients

Nutritional supplements may be provided where intake is low, and sometimes patients may need to be tube fed or receive diets of different textures to ensure eating and drinking is safe. Patients receiving nutritional support whilst they are in hospital will be followed up after discharge to review their progress.

Within the dietetic service as a whole there are a small number of dieticians (a total of 48 hour per week) who are part of specialist multidisciplinary neurological care teams at the Western General Hospital (DCN) and at the Lanfine and Charles Bell neurological rehabilitation services at the Astley Ainslie Hospital. People with MECFS are able to access the dietician based at the Regional Unit for Infectious Disease.
The Complex Enteral Nutritional Team (CENT) also provides support to people with neurological conditions.

Anyone with any neurological condition can be referred to the dietetic service. In the last year, 117 people with neurological conditions were referred to the service, 9 of these had Motor Neurone Disease and 23 had Multiple Sclerosis. Even within a tiered model of care which supports multidisciplinary teams to provide nutritional support and advice, this represents a very small proportion of the population with neurological conditions and supports the perception of the Dietetic Service that they are still seeing people “only when they are far down the line”.

**What do we need to do?**

We need to ensure that the integrated generic care pathway includes dietetics and is specific on screening using the MUST (tool).

We need to continue to develop the role of specialist nurses and the relationships with the dietetic service.

We need to ensure that a holistic approach to neurological care includes nutritional care and raise the profile of nutrition across the care pathway.

We need to develop patient’s confidence in managing nutrition and their awareness of their own nutritional status so that they can identify when further support may be required.

We need to develop the use of TRAK to allow us to check that we are recording information on nutrition, and review patient’s nutritional status.
APPENDIX 1: Neurological Voices Terms of Reference

Introduction

The Lothian Neurological Voices are a group of patients and carers, committed to working together to improve care and services for people with neurological problems across Lothian. They are part of a national initiative by the Scottish Neurological Alliance.

Membership of the group is open to patients and carers who are, or have been affected by a neurological condition and live in the Lothian region. They must also have participated in a Neurological Alliance Voices Training course.

Members are involved in a personal capacity and do not formally represent or report to any Condition Specific Organisation. Although people can draw upon what happened when they were treated, the role is to consider, reflect and offer opinion on issues affecting patient care. It is not about any one person’s story alone.

Purpose

The purpose of the Group is to work in partnership with NHS Lothian (and potentially other organisations) to provide advice, constructive criticism, views and experiences of people living with a range of neurological conditions in order to:

1. Shape and inform the drafting of Neurological service development plans and priorities for Lothian.

2. Identify gaps in service provision, help and advice which should be prioritised in the implementation plan.

3. Ensure that plans and developments focus on patient and carer needs.

4. Review and comment as requested on policy documents, patient information leaflets and any Neurological service matter in which user input might be helpful.

Governance arrangements

The Chair of Lothian Neurological Voices will be elected by members of Lothian Neurological Voices.

Staff of NHS Lothian, voluntary sector organisations, local authorities will attend subject to the agreement of the Chair.

The NHS Lothian Leads for Neurological Care Improvement (or deputies) will be the NHS Lothian link with the Neurological Voices Group.
The Chair and a second member of the Voices Group as appropriate will be members of the NHS Lothian neurological care improvement group.

NHS Lothian will provide administrative support for Neurological Voices meetings and all travel expenses or other appropriate expenses for up to 15 members of Neurological Voices for a minimum of 8 meetings a year and for attendance at the Neurological Care Improvement Group.

NHS Lothian will seek to provide expenses for attendance at additional meetings or events on request.

The need to publicise the work of the Voices Group is recognised. This might be achieved by making minutes of the meetings available on an appropriate website.

All meetings will be noted. Each meeting will have an agenda agreed with the Chair of the group.

Agreed 12 April 2013
APPENDIX 2: How Are We Doing On Our Vision For Ways Of Working?

Score each of the following aspects of our vision on a scale of 1 to 5 where
5 = we have achieved this aspect of the vision
1 = not at all

Average score from the Neurological Care Improvement Group in rank order (highest achievement first)
Responses =11 (out of 19) 58%

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<th>Score</th>
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<td>4.0</td>
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<tr>
<td>We have some good arguments</td>
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</tr>
<tr>
<td>We find ways to communicate and work together that are as productive and effortless as possible</td>
<td>3.2</td>
</tr>
<tr>
<td>Learning from patient’s experiences is part of the way that services operate</td>
<td>3.0</td>
</tr>
<tr>
<td>We are able to have challenging discussions about how current resources might be used differently to improve care and meet needs</td>
<td>2.9</td>
</tr>
<tr>
<td>We recognise and challenge usual assumptions and terminology</td>
<td>2.9</td>
</tr>
<tr>
<td>The identity of a neurological service in Lothian which recognises and values the multiple disciplines and specialties which contribute to this, which staff feel part of and which patients feel they are part of also</td>
<td>2.8</td>
</tr>
<tr>
<td>The outcomes for patients are articulated and measured (where possible)</td>
<td>2.7</td>
</tr>
<tr>
<td>There is a picture of who we are looking after that is as clear as possible</td>
<td>2.6</td>
</tr>
<tr>
<td>There is a clear as possible picture of other people who need or would benefit from neurological care</td>
<td>2.6</td>
</tr>
<tr>
<td>Some significant changes to the way resources are currently used to improve care and cost effectiveness of care</td>
<td>2.6</td>
</tr>
<tr>
<td>There are established ways of working which support strategic development as well as service delivery and improvement</td>
<td>2.5</td>
</tr>
<tr>
<td>Resources and capacity are used efficiently and we recognise that good care is about all aspects of service provision from administration to clinical communication</td>
<td>2.5</td>
</tr>
<tr>
<td>We work together to understand and address immediate pressures</td>
<td>2.5</td>
</tr>
<tr>
<td>There are full care pathways for as many conditions as possible</td>
<td>2.4</td>
</tr>
<tr>
<td>There is a shared infrastructure to support this neurological service</td>
<td>2.3</td>
</tr>
<tr>
<td>There is a list of interventions that we currently provide and a list that we aspire to provide or are on the horizon</td>
<td>2.3</td>
</tr>
<tr>
<td>There is a picture of people who do not fit into the care pathways we develop and of our response/how to help</td>
<td>2.1</td>
</tr>
<tr>
<td>There is a clear statement of the resources we are currently using to provide neurological care</td>
<td>2.1</td>
</tr>
<tr>
<td>There is a clear picture of the technology and systems currently supporting service</td>
<td>2.0</td>
</tr>
<tr>
<td>The value of intangible aspects of care provision (like phone hugs) is explicitly acknowledged</td>
<td>2.0</td>
</tr>
<tr>
<td>We will have a vision for research and development and the relationship with the University of Edinburgh which reflects our service aspirations and vice versa</td>
<td>2.0</td>
</tr>
<tr>
<td>We all manage to find time to be proactive rather than fire fighting</td>
<td>2.0</td>
</tr>
</tbody>
</table>
APPENDIX 3: Knowing Who We Are Looking After

There is a picture of people for whom we are providing care that is as clear as possible

The figures below are extrapolated from Neuro Numbers, produced by the Neurological Alliance UK. The UK figures were applied to a Lothian total population of 848,890 to give estimates for Lothian below.

In Lothian:

- 53,480 people living with a neurological condition (6% of total population)
- 42,784 people are affected by a neurological condition but able to manage on a day-to-day basis
- 5,348 are disabled by their neurological condition
- 1,872 require help with most of their daily activities
- 4,545 people living in a residential care home have a neurological condition

Table A below shows the projected numbers to end of year 2013-2014, of outpatient attendances and in-patient episodes for neurology and neurosurgery.

<table>
<thead>
<tr>
<th></th>
<th>Neurology</th>
<th>Neurosurgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient referrals</td>
<td>13,294</td>
<td>3,166</td>
</tr>
<tr>
<td>New outpatient</td>
<td>12,444</td>
<td>5,042</td>
</tr>
<tr>
<td>attendances</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Return outpatient</td>
<td>13,136</td>
<td>3,056</td>
</tr>
<tr>
<td>attendances</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All outpatient</td>
<td>25,580</td>
<td>5,686</td>
</tr>
<tr>
<td>attendances</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elective in-patient</td>
<td>506</td>
<td>1,194</td>
</tr>
<tr>
<td>admissions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non elective in-patient admissions</td>
<td>329</td>
<td>865</td>
</tr>
<tr>
<td>Elective day cases</td>
<td>1,289</td>
<td>469</td>
</tr>
<tr>
<td>Discharges</td>
<td>952</td>
<td>2,132</td>
</tr>
</tbody>
</table>
Table B below gives incidence and prevalence figures (where available) for selected symptoms and conditions based on the Lothian population of 848,890. Figures in bold are those provided from clinical databases/registers of patients. Other figures are projected from sources.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Incidence per year/new diagnosis</th>
<th>Prevalence</th>
<th>% per year seen by AAH outpatients</th>
<th>% new outpatients</th>
<th>GP attendances per year</th>
<th>% of GP attendances referred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple Sclerosis</td>
<td>81</td>
<td>1,700</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor Neurone Disease</td>
<td></td>
<td>65</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>680&lt;sup&gt;26&lt;/sup&gt;</td>
<td>2,500</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sub-arachnoid haemorrhage</td>
<td>137&lt;sup&gt;27&lt;/sup&gt;</td>
<td>700</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dystonia</td>
<td></td>
<td>552</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td></td>
<td>1,579</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Huntington’s</td>
<td></td>
<td>105</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td></td>
<td>424</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myasthenia Gravis</td>
<td></td>
<td>255</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain injury long term problems</td>
<td></td>
<td>1,935</td>
<td>4.2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate to severe brain injury (25/100,000, SABIN)</td>
<td>212 per year in Lothian</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild to moderate brain injury (308/100,000, SABIN)</td>
<td>2,614</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Epilepsy</td>
<td></td>
<td>5,924&lt;sup&gt;28&lt;/sup&gt;</td>
<td>14%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refractory epilepsy</td>
<td></td>
<td>1,184-1,777 (20-30% of cases)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional symptoms</td>
<td>172-339</td>
<td>16% (1,833)</td>
<td>Close to 100%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MECFS</td>
<td>3396</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headaches/migraine</td>
<td>127,334</td>
<td>19%&lt;sup&gt;29&lt;/sup&gt; (4860)</td>
<td>31,987&lt;sup&gt;30&lt;/sup&gt;</td>
<td>2-3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cluster headache</td>
<td>849</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic Migraine</td>
<td>25,467</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic tension type headache</td>
<td>16,978</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke (to be confirmed)</td>
<td>1800&lt;sup&gt;31&lt;/sup&gt;</td>
<td>6,112&lt;sup&gt;32&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<sup>26</sup> Based on CM presentation 680 incidence 13 per 100,000
<sup>27</sup> Admissions to DCN 13.14 700 cases open some SAH specialist nurses
<sup>28</sup> Based on GMS QOF data for 2012-2013
<sup>29</sup> DCN audit of 3 months found headaches accounted for 17% of all referrals (110/655)
<sup>30</sup> Figure based on 4.44 per 100 per year people over 16 McCrone P et al. Service use and costs for people with headache: a UK primary care study Journal of Headache and Pain 2011 12 617-623
<sup>31</sup> 1800 stroke syndrome per year in Lothian 420 under 65 source Mark Smith NHS Lothian Stroke Lead AHP
<sup>32</sup> BMJ Open 2011;1:e000269. doi:10.1136/bmjopen-2011-000269
<sup>33</sup> GMS QOF register stroke TIA C 15,000, Lothian
There is as clear a possible picture of people who need or would benefit from neurological care

Patients presenting at emergency departments, medical admissions units and on medical wards – Statistical Analysis

- Neuro Numbers estimates that around 10% of all emergency department attendances are for a neurological problem. In Lothian this would mean around 22,900 attendances per year
- 17% of GP consultations are for neurological symptoms, in Lothian this would be 918,000 per year
- 19% of acute hospital attendances are primarily for a neurological problem requiring treatment from a neurologist or neurosurgeon
- Approximately 9% of emergency admissions are for neurological problems (8,400) per year in Lothian
- Other studies indicate that that neurological problems result in 3-8% of emergency department attendances, 15-20% of medical unit admissions and 40% of inpatient on medical wards
- A study at the Royal Infirmary of Edinburgh (RIE) in 2005 found that 9% of acute medical attendances were neurological. The majority of those patients that did not have contact presented with epileptic seizures or headache. A study at RIE in 2005 found that 66% had no contact with a neurologist or neurosurgeon (an average of 52 patients per week) and that 40% of them may have benefitted. 42% of these patients were admitted to the medical admissions unit.

There is a picture of people who do not fit into the care pathways we develop and of our response/how to help

- People with functional symptoms
- Head and brain injuries
- Rare neurological conditions (other than Huntington’s and motor neurone disease)
APPENDIX 4: Statement of resources used to provide neurological care

We used the Integrated Resource Framework to begin to understand the resources being used to provide neurological care in Lothian. There are limitations of this approach. The data we used is from 2010 and 2011 and we were only able to identify people with a neurological condition from the recording of an SMR01, which meant that we could only identify people who had been day cases or in-patients. Overall what this means is that the resources used will be greater than those identified below.

Key findings were:

- The resource utilisation across health and social care of this relatively small proportion of people aged under 65 with a neurological condition is £50.3M - costs would be higher if people aged over 65 had been included in the analysis and costs higher still if the full range of health care provision (notably primary care and prescribing) had been available in the IRF.

- We were also able to identify the costs incurred by the cohort of patients with neurological conditions in other specialties, showing high levels of costs incurred in general medicine, rehabilitation medicine, anaesthetics, general psychiatry.

We identified costs in 2010-2011 of 1,804 people aged between 16 and 64 (compare this with previously cited figures of 42,784 people who are affected by a neurological condition but are able to manage on a day to day basis (5348) disabled by their neurological condition with who had an SMR01 record for a diagnosis of a neurological condition. The total financial cost for this year was £50.3M of which 28.6M was costs incurred in health care and £21.6M costs of social care. The costs refer to total health and social care costs, so could include care for other (non-neurological problems or conditions). The costs do not include pharmaceutical costs and the costs of medication.

Table 1 below shows the specialty costs from the same year, presented on the basis of what it costs to run the services (£5.6M per year for neurology and £10.0M for neurosurgery) and then looking at the costs to that specialty for the patients we identified.
| Table 1 Specialty costs based on activity captured by IRF and for patients identified with a diagnosis of a neurological condition |
|-------------------------------------------------|---------------------------------|
| | Activity based costs | Costs for patients identified with a neurological condition |
| Specialty costs – neurology | | |
| In-patients & day cases (direct care costs only) | £3,850,016 | £2,388,540 |
| | (£2,632,104) | (£1,854,777) |
| Out-patients | £1,776,721 | £265,679 |
| | (£1,353,862) | (£202,448) |
| Total | £5,626,738 | £2,654,220 |
| | (£3,985,966) | (£2,057,225) |
| Specialty costs – neurosurgery | | |
| In-patients and day cases (direct care costs only) | £9,380,173 | £2,231,738 |
| | (£6,764,795) | (£1,738,024) |
| Out-patients (direct care costs only) | £665,340 | £49,692 |
| | (£506,989) | (£37,865) |
| Total | £10,045,514 | £2,654,220 |
| | (£7,271,784) | (£1,775,889) |
| Other specialty costs (Top 5) | | Full costs |
| General medicine | £3,570,180 | |
| Rehabilitation medicine | £2,911,523 | |
| Anaesthetics | £3,088,707 | |
| General psychiatry | £2,105,656 | |
| Other specialty costs | | |
| A and E | £426,695 | |
| Infectious diseases | £286,207 | |

The IRF analysis is congruent with the information presented in the appendix on who would potentially benefit from neurological or neurosurgical care indicating the importance of support to patients in general medicine.
## APPENDIX 5: Membership of Neurological Care Improvement Group

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carl Bickler</td>
<td>GP and LTC Lead, Edinburgh CHP</td>
</tr>
<tr>
<td>Joanne Boyle</td>
<td>Planning and Commissioning Office, City of Edinburgh Council</td>
</tr>
<tr>
<td>Michelle Brogan (to February 2014)</td>
<td>Speech &amp; Language Therapist Manager, AAH</td>
</tr>
<tr>
<td>Audrey Burnside</td>
<td>Clinical Nurse Manager, Reproductive Medicine, RIE</td>
</tr>
<tr>
<td>Siddharthan Chandran</td>
<td>Professor of Neurology, RIE</td>
</tr>
<tr>
<td>Julie Collins</td>
<td>Clinical Project Support, WGH</td>
</tr>
<tr>
<td>Jane Dalrymple (from November 2013)</td>
<td>Assistant Programme Manager, Strategic Planning, Waverley Gate</td>
</tr>
<tr>
<td>Stewart Donald</td>
<td>Consultant Community Rehabilitation, AAH</td>
</tr>
<tr>
<td>Diane Fraser</td>
<td>Clinical Lead Speech and Language Therapist, DCN, WGH</td>
</tr>
<tr>
<td>Sue Gibbs</td>
<td>Quality &amp; Safety Assurance Lead, Pentland House</td>
</tr>
<tr>
<td>David Gillespie</td>
<td>Consultant Clinical Neuropsychologist, AAH</td>
</tr>
<tr>
<td>Joanna Gouick</td>
<td>Head of Clinical Neuropsychology, AAH</td>
</tr>
<tr>
<td>Belinda Hacking</td>
<td>Consultant Clinical Psychologist, WGH</td>
</tr>
<tr>
<td>Mark Hamilton</td>
<td>Assistant Service Manager, Neurosciences, Scoliosis &amp; Epilepsy, WGH</td>
</tr>
<tr>
<td>Helen Holden</td>
<td>Physiotherapy Manager, Liberton Hospital</td>
</tr>
<tr>
<td>Jane Hopton</td>
<td>Assistant General Manager, Strategic Planning, Waverley Gate</td>
</tr>
<tr>
<td>Conor Maguire</td>
<td>Consultant Physician, Medicine of the Elderly, WGH</td>
</tr>
<tr>
<td>Patrick Mark</td>
<td>Neurological Voices Representative and OMG Representative</td>
</tr>
<tr>
<td>Fiona Mitchell (Chair)</td>
<td>Director of Operations, Women &amp; Children, RHSC</td>
</tr>
<tr>
<td>Sheena Muir</td>
<td>Assistant General Manager, AAH</td>
</tr>
<tr>
<td>Catriona Simpson</td>
<td>Assistant Programme Manager, Strategic Planning, Waverley Gate</td>
</tr>
<tr>
<td>Alison Stewart</td>
<td>Lead Parkinson’s Nurse Specialist, WGH</td>
</tr>
<tr>
<td>Iain Todd</td>
<td>Consultant Rehabilitation Medicine, AAH</td>
</tr>
<tr>
<td>Belinda Weller</td>
<td>Consultant Neurologist, WGH</td>
</tr>
</tbody>
</table>
APPENDIX 6: Generic Care Pathway

PRIMARY CARE

Patient presents to GP  
Initial assessment and investigations by GP  
GP diagnosis OR refer to consultant OR seek specialist advice on referral  
Advice on referral via RefHelp

REFERRAL AND TRIAGE FROM PRIMARY CARE

RefHelp maximisation  
• referral guidelines are in place  
• individual specialties need to agree and state what is the cohort of patients they wish to see  
• individual specialties need to agreed and state what is the cohort of patients they would not wish to see  
• what information is expected on a referral (SCI protocol)  
• design a SCI protocol – consistent data set

Process in place through RefHelp and triage which gives details of how to refer for:  
• appointing  
• e-advice  
• managed access diagnostics

RefHelp is reviewed annually

REFERRAL AND TRIAGE FROM OTHER SPECIALTIES/A&E

SPECIALTY CARE PATHWAY

Diagnostic/symptom assessment pathway specified  
Symptom management/disease modification pathways specified  
Relapse prevention specified  
Rehabilitation planning is in place

Outpatient/consultant diagnosis on recorded on TRAK  
Referral to specialist nurse for register, confirm diagnosis is on TRAK and/or follow-up  
Early MDT review and assessment after diagnosis  
Clarity on stepped care  
Psychological interventions clearly defined within pathway (even if cannot be delivered at this stage)  
Neuropsychological assessments and interventions clearly specified within the pathway  
Referral to rehabilitation
ARRANGEMENTS FOR INTEGRATED ON-GOING CARE IN PLACE

Agree how the most high-risk patients are identified
When patient is seen
Diagnosis recorded
Individual care plan (telling GP of possible future GP management plans if this one ‘fails’ – low risk) – this can be seen as a clinical anticipatory care plan
Risk assessing each patient and agreeing pathway of follow-up etc for those most at risk
Provide tiered patient and carer advice (again risk stratifying patients)
Agree whether patient needs review in outpatients, discharge or fast-track back
Develop consistent outpatient letter dataset
Develop anticipatory care plan if appropriate
Admission to hospital/attendance at A&E generates automatic referral to specialist nurse

Development of MDT (in relevant specialty areas) To discuss high-risk patients (either in the hospital, in the community or seen in OPD) – this allows nurse specialist, outpatient services, in patients, rehab and community services to have a coherent and efficient approach to individuals

**Multi-disciplinary care plan** approach for complex cases/high-risk cases ensures:
- role of GP maximised
- role of community nursing maximised
- social care maximised
- carer support maximised

Role of telephone advice (for whom, by whom, and how – one contact number for patients and carers)

Access to further rehabilitation if required based on stepped care model

Support for self-care

INFRASTRUCTURE

Pathway/performance monitoring in place
Shared clinical record linked computer systems
Ability to follow-up/identify people lost to follow-up
Specialist nurses have direct access to consultant and booking for clinics
APPENDIX 7: NEUROPSYCHOLOGY MATRIX

Clinical Neuropsychology Matrix

1.0 Introduction

This Neuropsychology Matrix draws on The Matrix 2011: A Guide to Delivering Evidence-Based Psychological Therapies in Scotland, which was produced to enable Health Boards to provide the most effective psychological treatments for their populations. The Matrix 2011 presents a guide to the delivery of evidence-based therapies, such that mental health targets (e.g. the HEAT target relating to access to psychological therapies) can be achieved.

However, The Matrix 2011 does not cover all diagnoses or all patient groups; individuals with neurological illness are one group not covered by the document. Whilst many of the psychological difficulties experienced by people with a neurological illness are similar to those found in the non-neurologically impaired population, some of their needs are specific and warrant special consideration.

This document attempts to draw together the types of evidence-based activities carried out by Clinical Neuropsychologists working in an acute neuroscience setting such as DCN. It outlines the types of work undertaken by Clinical Neuropsychologists and the service and patient and family benefits that can be expected from this work. The document then considers how individuals with one neurological diagnosis, subarachnoid haemorrhage (SAH) access Clinical Neuropsychology services, and the input someone with SAH (as well as their family, and the team supporting them) can expect.
## Table of Clinical Neuropsychological work in the acute setting

<table>
<thead>
<tr>
<th>TYPE OF WORK</th>
<th>REASON FOR REFERRAL</th>
<th>QUESTIONS ASKED BY REFERRER</th>
<th>SERVICE BENEFITS</th>
<th>PATIENT/FAMILY BENEFITS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment-focused</td>
<td>To determine an individual's level of cognitive/emotional/behavioural functioning to aid neurological diagnosis</td>
<td>Does the patient's cognitive profile suggest a diagnosis of Alzheimer's disease or fronto-temporal dementia? To what extent do cognitive and emotional deficits reflect organic illness versus a functional illness, functional overlay, or the effects of mood or motivational problems?</td>
<td>Improves diagnostic accuracy</td>
<td>Timely diagnosis relieves anxiety and enables patients to access appropriate treatment and support (thereby enhancing quality of life)</td>
</tr>
</tbody>
</table>

| 2.0.1. Diagnostic assessment |  |  | Allows correct diagnosis to be reached in the shortest amount of time | Allows appropriate treatment to be given to patients whose deficits do not reflect (or not wholly reflect) organic disease: without accurate diagnosis these patients tend to have multiple medical appointments and unnecessary investigations |

We will meet the requirement (set by Neurological Health Standards) for people with neurological problems not explained by disease to access appropriate diagnostic services.
<table>
<thead>
<tr>
<th>TYPE OF WORK</th>
<th>REASON FOR REFERRAL</th>
<th>QUESTIONS ASKED BY REFERRER</th>
<th>SERVICE BENEFITS</th>
<th>PATIENT/FAMILY BENEFITS</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.0.2. Assessment of current functioning</td>
<td>To determine an individual's (cognitive) strengths and weaknesses</td>
<td>What has been the impact of head injury on the patient's memory and decision-making?</td>
<td>Ward and rehabilitation professionals get a better understanding of the patient's level of functioning. This allows them to set realistic goals and to give appropriate advice</td>
<td>Patients get a better understanding of the effects of their neurological illness: this improves their awareness (a fundamental building block of successful rehabilitation) and leads to better emotional and psychosocial outcomes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How can we explain the patient's difficulties in undertaking self-care activities on the ward?</td>
<td>Allows rehabilitation to be started immediately</td>
<td>Patients will have better medical and functional outcomes because psychological adjustment leads to better compliance with medication and treatment recommendations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What is the patient's capacity to make decisions about their treatment and subsequent discharge?</td>
<td>Facilitates safe and effective discharge (i.e. improves patient flow)</td>
<td>Family understand what they are dealing with, and know how to support the patient</td>
</tr>
<tr>
<td>TYPE OF WORK</td>
<td>REASON FOR REFERRAL</td>
<td>QUESTIONS ASKED BY REFERRER</td>
<td>SERVICE BENEFITS</td>
<td>PATIENT/FAMILY BENEFITS</td>
</tr>
<tr>
<td>-------------</td>
<td>---------------------</td>
<td>-----------------------------</td>
<td>----------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>2.0.3. Pre-surgical assessment</td>
<td>To determine an individual’s suitability for neurosurgical intervention</td>
<td>Is the patient a good candidate for surgery?  What is the patient likely to be left with (cognitively) after surgery?  What are the risks of surgery to this patient from a cognitive point of view?</td>
<td>Better patient selection for surgery (leading to better outcomes and fewer avoidable complications)</td>
<td>Patients will receive the surgeries that will benefit them in a timely way  Pre-surgical counseling can be offered to individuals (and families) where there is a risk to cognitive functioning after surgery. Patients make informed decisions about the risks/benefits from any procedure</td>
</tr>
<tr>
<td>2.0.4. Outcome assessment (e.g. of medical or surgical intervention)</td>
<td>To determine the impact of neurological (or neurosurgical) intervention at the cognitive level</td>
<td>How has this combination of anti-epileptic medication affected the patient cognitively?  Has the tumour removal improved or worsened this patient’s memory (and if so, by how much)?</td>
<td>Allows the effectiveness of interventions to be determined. This is essential for the improvement of services and the overall drive to provide the most effective, safe treatments</td>
<td>Patients and families understand the effects of an intervention (which might otherwise be difficult for them to appreciate). This leads to improved patient awareness and better psychosocial outcomes</td>
</tr>
<tr>
<td>TYPE OF WORK</td>
<td>REASON FOR REFERRAL</td>
<td>QUESTIONS ASKED BY REFERRER</td>
<td>SERVICE BENEFITS</td>
<td>PATIENT/FAMILY BENEFITS</td>
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<tr>
<td>2.0.5. Prognostication</td>
<td>To determine the likely recovery of an individual’s neuropsychological deficits</td>
<td>How much recovery in attentional functioning can be expected in the next six months? What is the likelihood that the patient will be able to return to work in their usual, or adapted, roles? What package of care is this patient likely to require?</td>
<td>Allows clinicians to provide accurate information to patients and families (and so not create unrealistic expectations, which can be very difficult to shift at later stages of the patient’s journey)</td>
<td>Helps patients and families to plan their lives, and make informed decisions about life-decisions (e.g. return to work; care arrangements)</td>
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<tr>
<td>Therapy-focused</td>
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<tr>
<td>2.0.6. Cognitive rehabilitation</td>
<td>To lessen the impact of an individual’s cognitive difficulties</td>
<td>Can the patient be helped to cope with their cognitive deficits more effectively? What are the best ways to improve the patient’s planning and organizational skills in the home and workplace?</td>
<td>Patients are encouraged to self-manage and accommodate to their cognitive difficulties (where appropriate); this is important for longer-term adjustment, and reduces patients’ reliance on formal, costly support (later in the pathway)</td>
<td>Patients improve their level of independence and therefore better functional and psychosocial outcomes are achieved Patients are better able to retain employment Family strain is reduced</td>
</tr>
<tr>
<td>TYPE OF WORK</td>
<td>REASON FOR REFERRAL</td>
<td>QUESTIONS ASKED BY REFERRER</td>
<td>SERVICE BENEFITS</td>
<td>PATIENT/FAMILY BENEFITS</td>
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</tr>
<tr>
<td>2.0.7. Promotion of coping</td>
<td>To treat mood problems and adjustment disorders</td>
<td>Can the patient’s depressive disorder be treated non-pharmacologically?</td>
<td>Emotional problems are a significant barrier to engagement in rehabilitation: improving mood outcomes is key to successful rehab engagement and so more effective use of time-limited nursing and allied health professional input</td>
<td>Patients improve their level of independence and therefore functional and psychosocial outcomes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How can the patient be helped to gain awareness of the impact of their brain injury?</td>
<td>There will be less reliance on anti-depressant prescribing (in line with Government policy)</td>
<td>Patients are better able to retain employment</td>
</tr>
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<td></td>
<td></td>
<td>What are the best ways for the team to promote the patient’s ability to cope their illness (and what appears to be getting in the way of them managing their condition)?</td>
<td>More patients will be enabled to return to, and remain in, employment</td>
<td>Family strain is reduced</td>
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<td>Patients are less reliant on anti-depressants or other psychoactive drugs, and are better able to make more effective use of their own resources (consistent with self-management principles)</td>
</tr>
<tr>
<td>TYPE OF WORK</td>
<td>REASON FOR REFERRAL</td>
<td>QUESTIONS ASKED BY REFERRER</td>
<td>SERVICE BENEFITS</td>
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</table>
| Behaviour-focused            | To reduce the frequency and severity of challenging behaviour exhibited by the person with neurological illness | How can the frequency of shouting be reduced on the ward?  
What steps can be taken to improve the patient's tolerance for rehabilitation? | The patient can be managed more effectively (i.e. with a less intensive nursing resource, and less reliance on medication) in the hospital environment  
Nurses and therapists are able to engage the patient in rehabilitation  
The patient can be discharged more efficiently  
Institutional care can be avoided for some patients | The patient can be integrated into their community more successfully  
Quality of life is improved for the patient  
Caregiver and family stress is reduced |
<table>
<thead>
<tr>
<th>TYPE OF WORK</th>
<th>REASON FOR REFERRAL</th>
<th>QUESTIONS ASKED BY REFERRER</th>
<th>SERVICE BENEFITS</th>
<th>PATIENT/FAMILY BENEFITS</th>
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<tbody>
<tr>
<td><strong>Staff-focused</strong></td>
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<tr>
<td>2.0.9. Staff training and supervision</td>
<td>To enable all staff to deliver psychologically-informed care</td>
<td>What steps can nursing staff take to increase patients’ independence in self-care?</td>
<td>Staff will feel more supported in their work: the psychological aspects of work with people with complex neurological problems is often rated the most difficult and stressful</td>
<td>Patients will have better emotional and psychosocial outcomes when all staff deliver psychologically-informed care</td>
</tr>
<tr>
<td></td>
<td>To increase colleagues’ level of knowledge and skill in psychological assessment and low-intensity intervention</td>
<td>What are the best ways for medical colleagues to pick up cognitive issues during outpatient clinic appointments?</td>
<td>Psychological support will be delivered within a matched/stepped-care model of service delivery. Patients will be matched to the least intensive intervention to provide health gain (and not immediately 'stepped up' to specialist psychological services)</td>
<td>Quality of life is improved for the patient</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How can Occupational Therapy colleagues be supported in the administration and interpretation of cognitive assessments?</td>
<td>Patients will be offered the most appropriate cognitive assessment, at the right time, with accurate interpretation of results</td>
<td>The total healthcare experience will be of higher quality</td>
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<td>There will be fewer complaints from patients and families (a significant proportion of complaints emerge when psychological issues are poorly attended to)</td>
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<tr>
<td>TYPE OF WORK</td>
<td>REASON FOR REFERRAL</td>
<td>QUESTIONS ASKED BY REFERRER</td>
<td>SERVICE BENEFITS</td>
<td>PATIENT/FAMILY BENEFITS</td>
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<tr>
<td>Family-focused</td>
<td>2.0.10. Carer/family interventions</td>
<td>To improve psychosocial outcomes for the carers and families of individuals with neurological illness</td>
<td>Can steps be taken to improve the family’s acceptance of neurological illness? How do we manage the marked level of distress shown by the patient’s partner when she visits? How can the family be encouraged to be more involved in discharge planning?</td>
<td>Support from families is important for patients to reach optimum levels of independence and to avoid (or delay) institutional care: support provided to caregivers and families helps informal care to be maintained in the longer term When family stress is reduced, families can play an important role in facilitating safe and effective hospital discharge</td>
</tr>
<tr>
<td>TYPE OF WORK</td>
<td>REASON FOR REFERRAL</td>
<td>QUESTIONS ASKED BY REFERRER</td>
<td>SERVICE BENEFITS</td>
<td>PATIENT/FAMILY BENEFITS</td>
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</tr>
<tr>
<td>Research and service</td>
<td>To advance the evidence base for assessment and treatment</td>
<td>What is the evidence for low-intensity psychological interventions in patients with neurological illness? What are the cognitive, emotional and behavioural outcomes for patients following temporal lobe surgery for epilepsy?</td>
<td>Allows us to provide the most effective interventions (to the right patients, at the right time, with the right level of intensity, etc): this is especially important in areas where there has been relatively little previous research to guide clinical practice Allows us to continually improve our services, and make best use of limited resources</td>
<td>Patients will have better outcomes across a range of domains</td>
</tr>
<tr>
<td>development</td>
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### 3.0 Clinical examples

This section gives an overview of the neuropsychologist’s work with one neurological group, patients with subarachnoid haemorrhage (SAH).

#### 3.0.1 SAH

**3.0.1.1 Neuropsychological impact of SAH**

Although patients who survive SAH tend to have good physical and basic functional outcomes (for example, 72% of patients gain independent mobility; Visser-Meily *et al*., 2009), cognitive and emotional problems are present in a significant number of patients after their haemorrhage (Pritchard *et al*., 2004). In fact, the problems most frequently cited by survivors of SAH when they leave hospital are in the cognitive and psychosocial domains.

In the cognitive domain, a recent review reported high rates of memory impairment (up to 60% of SAH survivors), language difficulties (up to 75%) and executive impairment (up to 75%) (Al-Khindi *et al*., 2010). Cognitive impairments have an impact on patients’ day-to-day...
functioning, including Activities of Daily Living (ADLs), instrumental ADLs, return to work and quality of life. For example, when driving on a busy city street, a survivor of SAH might experience transient lapses of concentration and feelings of being overwhelmed. The cognitive impairment and real-world deficits that accompany SAH often go undetected and patients who have apparently made a “good recovery” (e.g. GOS 5) may still experience profound cognitive deficits such that they struggle to resume their pre-illness lives. Most SAH survivors are, of course, relatively young; in their most productive years; and have major responsibilities with respect to work and family.

Mood disturbances are common after SAH. Anxiety and depressive disorders have been noted in up to half of patients after SAH, and evidence suggests that mood problems do not necessarily remit in the 18 months after haemorrhage (Powell et al., 2004). For the majority of SAH patients, the experience is an extremely traumatic one. Even in those with amnesia for the events leading to admission, psychological trauma is still a common outcome when patients are shocked to wake up on a hospital ward, often with physical and cognitive impairments, with no idea of how they got there, and then informed that they have suffered a brain haemorrhage and very nearly died (Jarvis, 2002; Thompson et al., 2011). Unsurprisingly, post-traumatic stress disorder (PTSD) has been found in up to one in three patients (Al-Khindi et al., 2010).

3.0.1.2. The roles of the Clinical Neuropsychologist

Assessment of current functioning (2.0.2)

It is important to obtain an accurate picture of a patient’s cognitive deficits, to help establish the full impact of SAH. Sometimes cognitive assessment can be undertaken by the non-neuropsychologist using valid and reliable screening measures (e.g. the Montreal Cognitive Assessment (MoCA); Schweizer et al., 2012), with the Clinical Neuropsychologist having a role in training others in test administration and interpretation (i.e. 2.0.9 – Staff training and supervision). However, a proportion of patients will require more detailed assessment to determine the true nature of their deficits, for at least three important reasons. Firstly, assessment must be tailored to an individual’s estimated pre-morbid level of intellectual ability; an intellectually able patient may ‘pass’ a screening test even when a decline in cognitive functioning has occurred. Secondly, assessment requires careful consideration of executive functioning, which by its complex nature is difficult to pick up using screening tools or on functional assessment alone. Executive test performance is associated with failure to return to work, and so the Clinical Neuropsychologist’s assessment is a key source of information for future planning for the individual with SAH, their family, and service providers (i.e. 2.0.5 – Prognostication). Thirdly, there is evidence that self-reported deficits in cognitive functioning following SAH do not always correlate with the results from objective tests: the Clinical Neuropsychologist can assist survivors of SAH and their families to obtain an accurate understanding of their actual strengths and weaknesses, which is vitally important for promoting patient adjustment and building resilience.

Prognostication (2.0.5)
See above.

_Cognitive rehabilitation (2.0.6)_
Cognitive rehabilitation refers to the provision of systematic, functionally orientated activities that are based on an assessment and understanding of patients' brain-behavioural deficits (i.e. as obtained at 2.0.2 – Assessment of Current Functioning). There is a substantial body of evidence demonstrating that patients with stroke, including SAH, benefit from cognitive rehabilitation, particularly strategy training in attention, memory and executive functioning (Cicero _et al._, 2005). The Clinical Neuropsychologist is able to provide individually tailored advice about cognitive compensatory techniques in order to promote self-management. Quite frequently cognitive impairment and mood difficulties go hand-in-hand after SAH (Kreiter _et al._, 2013), and it is here that the expertise of the Clinical Neuropsychologist is especially helpful. If for example, a patient has memory impairment and depression, and the depression is a result of the patient being unable to cope with current memory demands, the Clinical Neuropsychologist can devise an individualised strategy approach to improve the patient’s functioning. In other words, intervention is most appropriately provided by a single ‘system’, without the need for anti-depressant medication or mental health referral.

_Promotion of coping (2.0.7)_
As indicated above, SAH frequently results in disabling psychological trauma. The Clinical Neuropsychologist plays a crucial role in addressing the emotional sequelae experienced by SAH survivors. They can provide psycho-education about presenting symptoms, and cognitive-behavioural therapy for mood disturbance and fatigue. In particular, the assessment and treatment of PTSD requires the Clinical Neuropsychologist’s advanced psychological skills. An integrated neuropsychological-specialist nursing programme has recently been described in the literature (Thompson _et al._, 2011), a time-limited approach that is clinically effective, associated with high patient satisfaction and which saves significant amounts of money on time off work compared to treatment as usual, which often entails a significant delay between acute and long-term services (e.g. Pritchard _et al._, 2004).

_Staff Training and Supervision (2.0.9)_
See above.

_Carer/family interventions (2.0.10)_
Considering the life-threatening nature of SAH it is understandable that distress may be experienced not only by the SAH survivor, but also by his or her family. Indeed, family members can have even higher levels of emotional distress than patients (Buchanan _et al._, 2000). A quarter of spouses in one study met criteria for PTSD (Noble & Schenk, 2008). The impact of relatives’ fear of recurrence on the patient’s recovery was, until recently, unknown. An important recent study (Covey _et al._, 2013) has identified that not only were significant others more fearful of
SAH recurrence than patients, patient’s functional and social recoveries may be compromised if family members are excessively fearful about recurrence and so overprotect and restrict day-to-day activities.

Psycho-education, counseling, and structured therapy can be offered to family members early after SAH. Intervention would be expected to benefit family members directly and survivors of SAH indirectly. Non-psychologist colleagues can be assisted, through training and supervision, to develop their ability to respond to families’ needs when fear and distress are present.

Research and audit (2.0.11)
Research and audit activities are central to the Clinical Neuropsychologist’s role. The Clinical Neuropsychologist may conduct their own research, or collaborate with colleagues on various studies. To take an example, it is important to be able to identify the origins of family members’ fears of recurrence because of their impact on patient recovery, and to investigate the best ways to manage these fears (the topic area of Dr Gillespie’s NRS Clinical Research Fellowship).

4.0 References

Buchanan et al. (2000). Differing perspectives on outcome after subarachnoid haemorrhage: the patient, the relative, the neurosurgeon. Neurosurgery, 46, 831-838.


Dr David Gillespie, January 2014
Appendix: Diagrammatic Neuropsychology Matrix
APPENDIX 8: Evidence Based Care Pathway for Functional Symptoms

**Functional Neurological Symptoms**

Functional Neurological Symptoms are symptoms such as blackouts and paralysis that are genuine but not due to a neurological disease. They are the second most common reason for a neurology outpatient visit in Scotland. They include dissonant (non-epileptic) attacks, functional limb weakness/movement disorder, sensory, visual, speech and cognitive symptoms.

**Specifics of pathway in NHS Lothian**

- **Inpatients**: will be seen within 24 hours (Mon-Fri) by neuropsychiatry team (including Videoelectroencephalography Patients)
- **Outpatients**: will be seen within 4 weeks by brief intervention therapists; within 12 weeks by complex care team
- **Patients from outwith NHS Lothian**: will be seen as appropriate before being passed back to local teams

**Personnel**

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
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<tbody>
<tr>
<td>Neurology Consultants (DCN)</td>
<td>Brief intervention therapist 2: Not funded/staffed</td>
<td>Neuropsychiatry: Dr. Alan Cavan, Dr. Julian Welch, Dr. Sarah Kennedy (Malcolm Psychiatry SLN)</td>
</tr>
<tr>
<td>Physiology: Michelle Thorne</td>
<td>Three therapists from nursing and physiotherapy backgrounds to work as specialist therapists in an integrated NHS team +/- physio assistant</td>
<td>Neurorehabilitation: Dr. Alan Cavan, Dr. Stuart Donald (AAM)</td>
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<tr>
<td>Other Secondary Care</td>
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## APPENDIX 9: Neurological Improvement Leadership Group – Membership List

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
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<tbody>
<tr>
<td>Jo Bennett</td>
<td>Clinical Governance Manager</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Carl Bickler</td>
<td>GP and Clinical Lead</td>
<td>Edinburgh CHP</td>
</tr>
<tr>
<td>Audrey Campbell</td>
<td>Clinical Nurse Manager, DCN</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Jacquie Campbell (Chair)</td>
<td>General Manager, Head and Neck</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Gemma Couser</td>
<td>Service Manager, DCN (from November 2014)</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Siddharthan Chandran</td>
<td>Professor of Neurology</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Marion Christie</td>
<td>Head of Health Services</td>
<td>West Lothian CHCP</td>
</tr>
<tr>
<td>Jim Crombie (Executive Lead)</td>
<td>Director of Scheduled Care</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Gillian Crosby</td>
<td>Senior Manager, Disability Services</td>
<td>City of Edinburgh Council</td>
</tr>
<tr>
<td>Jane Dalrymple</td>
<td>Assistant Programme Manager</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Stewart Donald</td>
<td>Consultant in Rehabilitation Medicine (Community)</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Lynne Douglas</td>
<td>AHP Director</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Alasdair Fitzgerald</td>
<td>Consultant in Neurorehabilitation</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Belinda Hacking</td>
<td>Consultant Clinical Psychologist</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Helen Holden</td>
<td>Physiotherapy Manager</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Rona Laskowski</td>
<td>Strategic Programme Manager</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Alison MacDonald</td>
<td>Head of Health</td>
<td>East Lothian CHP</td>
</tr>
<tr>
<td>Alisdair McDonald</td>
<td>Finance Manager, Costing &amp; Strategic Programmes</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Conor Maguire</td>
<td>Consultant Physician, Medicine of the Elderly</td>
<td>NHS Lothian</td>
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<tr>
<td>Patrick Mark</td>
<td>Chair, Neurological Voices</td>
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<tr>
<td>Sheena Muir</td>
<td>Assistant General Manager, Edinburgh CHP</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Alison Stewart</td>
<td>Lead Parkinson’s Specialist Nurse</td>
<td>NHS Lothian</td>
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<tr>
<td>Jon Stone</td>
<td>Consultant Neurologist and Honorary Senior Lecturer</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Belinda Weller</td>
<td>Consultant Neurologist &amp; Honorary Senior Clinical Lecturer</td>
<td>NHS Lothian</td>
</tr>
<tr>
<td>Sheena Wight</td>
<td>Occupational Therapy Manager (representing Allister Short, Head of Health)</td>
<td>Midlothian CHP</td>
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<td>TBC</td>
<td>Voluntary sector</td>
<td>Third Sector</td>
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<tr>
<td>TBC</td>
<td>Partnership</td>
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<td>West Lothian Council</td>
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APPENDIX10: Glossary

**Cardiac Rehabilitation**
Cardiac rehabilitation (CR) is a branch of rehabilitation medicine/Physical Therapy dealing with optimizing physical function in patients with cardiac disease or recent cardiac surgeries.

**Cognitive domain**
The theory and practice of adult education identifies four key domains of learning. The co
http://www.rcpsych.ac.uk/workinpsychiatry/cpd/coreprinciplesoflearning/doma
nsofbelearninggnitive domain (knowledge) learning about things

**Department of Clinical Genetics**
South East Scotland Genetic Service, David Brock Building Western General Hospital
The Department runs a number of general genetic clinics across Lothian, Borders and Fife. Several specialist clinics including Neurogenetics, Marfan Syndrome and Endocrine Genetics, are held in Edinburgh.
http://www.nhslothian.scot.nhs.uk/Services/A-Z/ClinicalGeneticsService

**Department of Clinical Neurosciences**
The Department of Clinical Neuroscience – which includes both neurology and neurosurgery – is currently sited at the Western General Hospital in Edinburgh. The department has three wards, operating theatres, diagnostic services and outpatient clinics. Neurology outpatients are also seen at St John’s Hospital in Livingston, the Royal Infirmary of Edinburgh, Roodlands Hospital and Leith Community Treatment Centre.
http://www.nhslothian.scot.nhs.uk/Services/A-Z/ClinicalNeuroscience

**Fronto-temporal dementia**
Frontotemporal dementia is one of the less common forms of dementia. The term covers a range of specific conditions. It is sometimes called Pick's disease or frontal lobe dementia.

**GMS Quality and Outcomes Framework**
The quality and outcomes framework (QOF) is part of the General Medical Services (GMS) contract for general practices and was introduced on 1 April 2004.
Healthcare Improvement Scotland

**Instrumental activities of daily living**
This phrase is used to encapsulate tasks/level of ability required to undertake same, such as ability to use a telephone, responsibility for own medications, ability to handle finances.
**Integrated Pathways of Care**
Care pathways are described variously as integrated care pathways, clinical pathways, critical pathways, care maps, or anticipated recovery pathways.


A care pathway is "anticipated care placed in an appropriate time frame, written and agreed by a multidisciplinary team.

It has locally agreed standards based on evidence where available to help a patient with a specific condition or diagnosis move progressively through the clinical experience.

It forms part or all of the clinical record, documenting the care given. It facilitates and demonstrates continuous quality improvement.

It includes patient milestones and clinical interventions noted on the day or stage that they are expected to occur.

**Integrated Resource Framework (IRF)**
The IRF helps partnerships to understand more clearly current resource use across health and social care, enabling better local understanding of costs, activity and variation across service planning and provision for different population groups.

**Lothian Neurological Care Improvement Group**
The group of stakeholders who met and delivered this Improvement Plan for Neurological Care across Lothian.

**Managed Services Network for Neurosurgery**
Neurosurgical services are provided in four cities in Scotland: Aberdeen, Dundee, Edinburgh and Glasgow, serving a population of 5.5 million people.

The Managed Service Network (MSN) is the first of its type in Scotland and has responsibility for the delivery of a single national service on four separate sites, ensuring a safe and sustainable service is achieved by appropriately locating sub-specialty work in specific centres, and is also responsible for Consultant appointments.

**ME-CFS**
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
This can include severe and debilitating fatigue, painful muscles and joints, disordered sleep, gastric disturbances, poor memory and concentration are commonplace. In many cases, onset is linked to a viral infection. Other triggers may include an operation or an accident, although some people experience a slow, insidious onset
**National Neurological Advisory Group (NNAG)**
The NNAG was set up in 2012 to oversee and support NHS Boards as they implement improvements through their 3 year Neurological Improvement Plans. In developing its work to support NHS Boards to meet the criteria contained within the Clinical Standards for Neurological Health Services the NNAG has put a number of work streams in place.

**Neurological Alliance of Scotland**
The Neurological Alliance of Scotland was launched in 2004 to ensure that neurological services are given priority at all levels of health and social care planning. Organisations representing neurological conditions or relevant issues, for example support for carers, are welcome to join the Alliance.

**Neurological Voices**
The Neurological Voices Programme prepares people with different neurological conditions (eg, Ataxia, Dystonia, Epilepsy, Huntington’s Disease, ME, Multiple Sclerosis, Parkinson’s Disease, Neuropathies and more) AND their informal carers to get involved in planning and improving neurological health services. It is run by the Neurological Alliance of Scotland, in partnership with local NHS Health Boards.

**Neurology**
The branch of medicine that deals with the nervous system, both normal and in disease.

**Neuropsychological deficits**
Measurement of cognitive strengths and weaknesses is an important aspect of neuropsychological assessment. Deficits in neuropsychological performance are of interest to clinicians, because they are thought to reflect a behavioural and measurable manifestation of underlying biological dysfunction. For instance, neuropsychological dysfunction frequently follows brain damage and is a common feature of many neurological disorders (Lezak, Howieson, and Loring, 2004).

**Neuropsychologist**
A clinical psychologist who specializes in assessing psychological status caused by a brain disorder.

**Neuro-rehabilitation**
Neuro-rehabilitation is a complex medical process which aims to aid recovery from a nervous system injury and to minimize and/or compensate for any functional alterations resulting from it.

**Neurosurgery**
Surgery performed on the nervous system, especially the brain and spinal cord. It includes the operative, non-operative, intensive care management and rehabilitation of patients with disorders affecting the brain and skull, spine and nervous system.
**NHS Lothian Strategic Planning Group**
This group was established to develop the priorities for strategic service redesign across NHS Lothian, taking account of population health needs and epidemiological information, health and healthcare horizon scanning, and service demand and capacity plans.

**Primary Care**
Health care provided in the community for people making an initial approach to a medical practitioner or clinic for advice or treatment.

**Progressive Neurological Conditions**
These conditions involve a progressive deterioration in functioning and are likely to affect the individual for life. They include amongst others multiple sclerosis, motor neurone disease, and Parkinson's disease. Some of the disorders progress more rapidly than others. Some are unpredictable and typically have periods of relapse and periods of remission. Communication problems associated with progressive neurological disorders may be similar to those caused by injury or other non-progressive disorders affecting the brain and the body's nervous (neurological) system.

**Psychosocial domain**
The theory and practice of adult education identifies four key domains of learning.
The psychosocial domain (social skills) learning to achieve things together and the social skills necessary to development in the other three domains.
http://www.rcpsych.ac.uk/workinpsychiatry/cpd/coreprinciplesoflearning/domainsoflearning

**RefHelp**
RefHelp is a system used by clinicians within NHS Lothian which provides up to date information about clinical specialties and assists GPs and other clinicians in making the best possible referrals for their patients.

**REH**
Royal Edinburgh Hospital

**Secondary Care**
The provision of a specialised medical service by a physician specialist or a hospital on referral by a primary care physician.

**Subarachnoid Haemorrhage**
A subarachnoid hemorrhage is an abnormal and very dangerous condition in which blood collects beneath the arachnoid mater, a membrane that covers the brain. This area, called the subarachnoid space, normally contains cerebrospinal fluid. The accumulation of blood in the subarachnoid space can lead to stroke, seizures, and other complications. Additionally, subarachnoid hemorrhages may cause permanent brain damage and a number of harmful biochemical events in the brain. A subarachnoid hemorrhage and the related problems are frequently fatal.