

# Neurosciences & the Senses Health Network

## 2008 Stakeholder Forum

### Report

Prepared by  
Health Networks Branch  
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## EXECUTIVE SUMMARY

The Neuroscience & the Senses Health Network Stakeholder Forum was held on 25 March 2008 at the City West Function Centre. An invitation was extended to 260 identified key stakeholders and approximately 65 participants attended the event. Representatives from clinical specialties, general health organisations, consumers, rural and metropolitan health services were present, as well as non-government organisations that provide services for the Neurosciences & the Senses Network.

### *Top 3 Priorities Identified*

- Models of Care and/or care aspects.
- Workforce.
- Commonwealth and State funding.

The barriers and enablers identified are broad and have been categorised in Tables 1 & 2.

### *Individual Reflection*

Participant response indicates that the Network could better meet the needs of its stakeholders through five key areas.

- Improving consultation/engagement.
- Improving communication.
- Increasing collaboration/networking.
- Addressing workforce/resources.
- Providing updates on data/research

Participant response indicates that the Network could better meet the needs of the areas/fields represented within its portfolio through six key areas.

- Addressing workforce/resources.
- Improving consultation/engagement.
- Addressing aspects of certain models of care or services.
- Increasing collaboration/networking.
- Improving communication.
- Addressing funding issues.



## 1. BACKGROUND

Health Networks have been set up as a part of the current health reform process to provide advice and direction on the delivery of health services across Western Australia.

Based on principles of cooperation and partnerships between key stakeholders, networks aim to improve the delivery of health services through coordination and integration of health and health related services. Further detail on the Health Networks can be found in the WA "Clinical Networks Framework" (<http://www.healthnetworks.health.wa.gov.au/publications/>).

The Neurosciences & the Senses Health Network (NSHN) was launched in March 2006 <http://www.healthnetworks.health.wa.gov.au/neuro/index.cfm>. The Network's Clinical Lead, Prof Bryant Stokes, was appointed in July 2005 and reappointed for another term in late 2007. The NSHN Executive Advisory Group was appointed in November 2005.

The NSHN Clinical Lead and Executive Advisory Group have provided leadership and coordination that enabled the Network to achieve key milestones for the disciplines represented, including Neurosurgery, Neurology, Ophthalmology and Ear, Nose and Throat.

Participation and input from a variety of people and organisations across different health care areas as well as the community is sought to ensure health care policy, planning and delivery is responsive to identified priorities and community need.

The NSHN held the launch and first stakeholder forum on 30 March 2006. The purpose of this forum was to provide an opportunity for clinicians to join with major stakeholders to explore the scope and begin the development of the NSHN. [http://www.healthnetworks.health.wa.gov.au/neuro/docs/Neuro\\_Workshop\\_Report.pdf](http://www.healthnetworks.health.wa.gov.au/neuro/docs/Neuro_Workshop_Report.pdf)

In 2006 a number of priorities were identified for initial development:

- Neurodegeneration (Alzheimer's & Dementia)
- Acquired Brain Injury (ABI)
- Neurotrauma (Spinal & ABI)
- Stroke

Additional conditions identified for development:

- Dual Diagnosis
- Neurodegeneration and Dual Diagnosis
- Long Term Care of Childhood to Adult Neurological Disease
- Ear, Nose & Throat (ENT)



## 2. NEUROSCIENCES & THE SENSES HEALTH NETWORK

### 2.1 Leadership

Prof Bryant Stokes was first appointed as the Neurosciences & the Senses Health Network (NSHN) Clinical Lead in July 2005.

Prof Stokes is a Consultant Neurosurgeon and Clinical Professor of Surgery at the University of Western Australia. He is also a past Chief Medical Officer of the Department of Health WA.

Prof Stokes has been involved in quality and safety issues for the past 15 years. He has held the position of Chairman of the Western Australian Council for Safety and Quality in Health Care since its inception in August 2002. He was also a member of the Australian Council for Safety and Quality in Health Care between 2000 and 2005.

Recently the Clinical Lead positions for each Network were reviewed by the Health Networks Branch and Prof Stokes was reappointed for another term as Clinical Lead for the NSHN.

### 2.2 Scope

The Neurosciences & the Senses Health Network includes the surgical sub-specialty of Neurosurgery; the medical sub-specialty of Neurology; and the surgical sub-specialties of Ophthalmology and Ear, Nose and Throat.

Specifically, the NSHN portfolio currently includes:

- Stroke - *Model of Stroke Care for Western Australia* endorsed in February 2006.
- Acquired Brain Injury.
- Epilepsy - *WA Epilepsy Services Model of Care* endorsed in May 2008.
- Motor Neurone Disease - *Motor Neurone Disease Services for Western Australia* undergoing stakeholder consultation.
- WA Eye Health Services - *WA Eye Health Services Development Plan*.
- Sensory Neural Deafness.

### 2.3 Community Engagement

The NSHN absolutely values the input of the community to the Network business. The NSHN Executive Advisory Group and project groups encourage consumer, general practitioner, non-government organisation and carer membership.

The NSHN is developing a Consumer Advisory Group that will strengthen the consumer and carer presence in the Network.



## 3. STAKEHOLDERS' FORUM

### 3.1 Aim

The aim of the Workshop was to bring together key stakeholders to explore the progress of the NSHN as well as strengthen development of the Network.

### 3.2 Objectives

The objective of the NSHN second stakeholder forum held on 25 March 2008:

- To inform the stakeholders of the NSHN progress.
- To review current priorities.
- To identify new priorities.
- To identify barriers that prevent best case for the priority conditions.
- To identify the enablers for the priority conditions.
- Encourage participation in Network business.
- Identify improvements to Network business.

### 3.3 Attendance

The Stakeholder Forum was held on 25 March 2008 at the City West Function Centre from 8.30am to 12.30pm.

Invitations were sent electronically to 260 key stakeholders that have registered to remain informed on the Neurosciences & the Senses Health Network on the Health Networks Branch database. A global email invitation was sent statewide to increase the communication and extend representation. Approximately 65 participants attended the workshop, which included representation from clinical specialties, allied health, general health organisations, consumers, country and metropolitan area health services and non-government organisations that provide services or have an interest in services for the NSHN.

Professor Bryant Stokes opened the forum and provided an overview of the NSHN progress and barriers since its launch in March 2006.

Mr Mark Slattery, Manager Health Networks Branch, presented an overview of the Health Networks Branch strategic direction and achievements.

Dr Peter Silbert, State Director of Neurology and NSHN Executive Advisory Group member, provided an overview of the NSHN process and progress on the *WA Epilepsy Services Model of Care* and the *Motor Neurone Disease Services for Western Australia*.

Ms Margitta Docters van Leeuwen, Development Officer Health Networks Branch and executive support to the Neurosciences & the Senses Health Network, facilitated the workshop.



### 3.4 Format

The format of the stakeholder forum was a facilitated workshop with participants working in groups to gather information and ideas around the following three focus questions:

- Identify and discuss new priorities.
- Barriers for top 3 priorities.
- Enablers for top 3 priorities.

The second part of the workshop component asked the stakeholders to reflect on the following two questions:

- How can this Network better meet your needs?
- How can this Network better meet the needs of your area/field?

### 3.5 Workshop Outcomes

#### *Group Discussion*

The stakeholder forum participants identified priority areas to be addressed within the health system rather than specific conditions. This indicates that the factors influencing care for the cohort of patients, carers and organisations represented by the NSHN are not necessarily condition specific but rather are consistent areas that impact on all or most of the conditions included in this portfolio.

The priorities that were determined by the participants fell broadly into seven categories (a comprehensive list of comments in **appendix 1**):

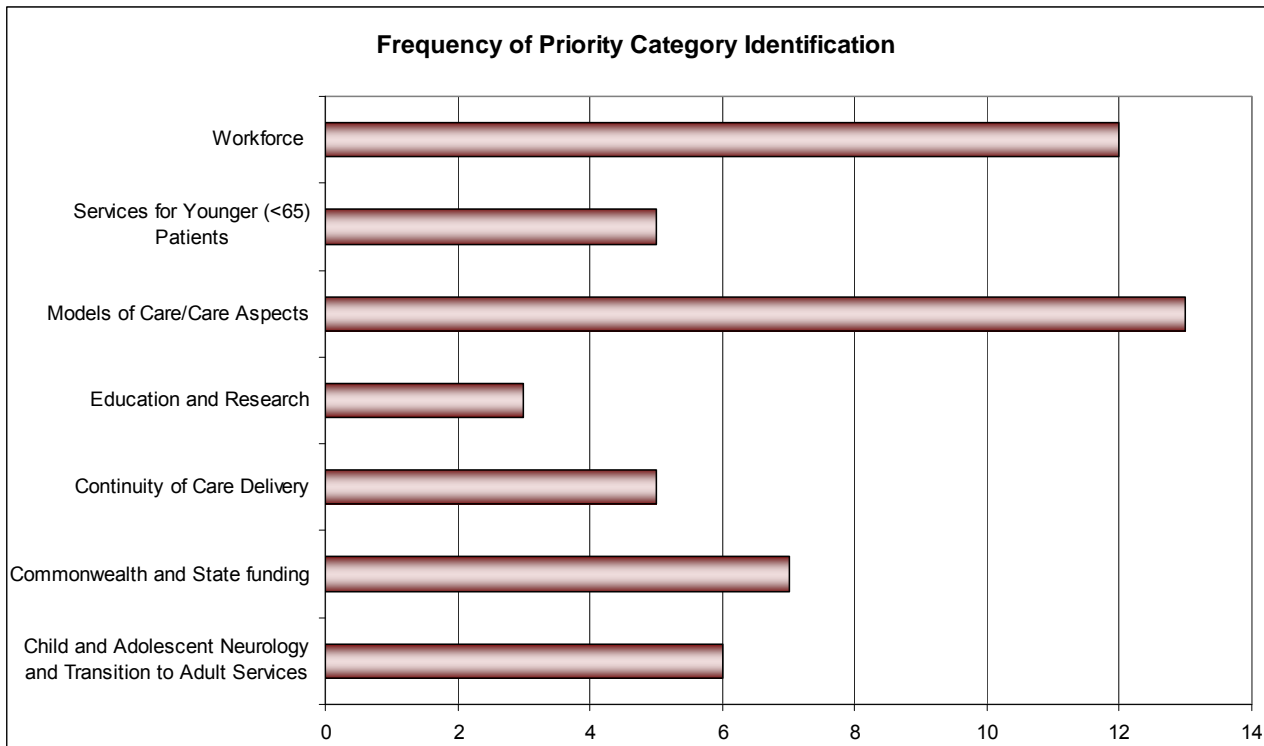
1. Workforce. Specifically staff support, training and professional development.
2. Continuity of care delivery. Specifically across state and federal boundaries, departments and non-government organisations.
3. Education and research, including prevention.
4. Commonwealth and State funding.
5. Services for younger (<65) patients.
6. Child and adolescent neurology and transition to adult services.
7. Models of Care or aspects of care to be addressed.

Total response results are represented in **Figure 1**.

Summary of barriers identified are represented in **Table 1**.

Summary of enablers identified are represented in **Table 2**.

**Figure 1: Frequency of Priority Categories - identified by participants during the group discussion.**



### *Barriers Identified*

**Table 1: Barriers identified by broad category**

Broad Category	Barriers Identified
Workforce	<ul style="list-style-type: none"> <li>▪ Rural access.               <ul style="list-style-type: none"> <li>i. Very hard to service whole of WA.</li> <li>ii. Some services do need high level of skill (inappropriate for primary settings).</li> <li>iii. Lack of support for clinicians to get experience in rural areas.</li> <li>iv. Lack of support for rural practitioners (though Telehealth can assist with this).</li> <li>v. Special needs of particular areas.</li> <li>vi. "Turf Protection".</li> </ul> </li> </ul>
Services for Younger (<65) Patients	<ul style="list-style-type: none"> <li>▪ Lack of needs based access &lt;65.</li> <li>▪ Lack of carer support               <ul style="list-style-type: none"> <li>i. Education</li> <li>ii. Rehabilitation</li> <li>iii. Respite (appropriate facilities)</li> </ul> </li> </ul>

<p>Models of Care or Care Aspects</p>	<ul style="list-style-type: none"> <li>▪ Consumer representation on Models.             <ul style="list-style-type: none"> <li>i. Tertiary centric models.</li> <li>ii. Doctor centric models.</li> <li>iii. Funding for change/models of care.</li> <li>iv. Closing the gaps in lack of services in community.</li> </ul> </li> <li>▪ Treatment not adequately stressed.</li> </ul>
<p>Education and Research</p>	<ul style="list-style-type: none"> <li>▪ Peer group appropriate models of education.             <ul style="list-style-type: none"> <li>i. Hard to demonstrate success of prevention/measure outcomes (epidemiological data/population health)</li> </ul> </li> <li>▪ Available time and funding to commence research. Curtin University students are currently able to engage in Speech Pathology Department quality assurance activities under supervision. The University has not yet developed a stream for Speech Pathology students to engage with teaching hospitals in joint clinical research as part of their undergraduate placement training.</li> </ul>
<p>Continuity of Care Delivery</p>	<ul style="list-style-type: none"> <li>▪ Gate keeping.</li> <li>▪ Services (including respite).             <ul style="list-style-type: none"> <li>i. Currently very fragmented &amp; have different access criteria.</li> <li>ii. Lack of directories of available services.</li> <li>iii. Interaction between agencies and integration between housing/ education/ health services.</li> </ul> </li> <li>▪ The key barrier to effective provision of a Model of Care which is coordinated with community services is the lack of access to community services themselves.</li> <li>▪ The community Speech Pathology services funded by Disability Services Commission are often able to accept referrals for these children (children with other Neurogenic communication disorders - Epilepsy, ABI) for their ongoing needs, there is often a long waitlist for services,</li> </ul>



	<p>which results in families accessing tertiary level services for longer than ideal.</p> <ul style="list-style-type: none"><li>▪ Transitioning children with Neurogenic communication and feeding disorders to local community services can be made more difficult when those services do not have the skills or knowledge to manage more complex cases.</li><li>▪ Integration of several agencies (who does what when and where?), distribution of resources, physical location of services.</li></ul>
Commonwealth and State Funding	<ul style="list-style-type: none"><li>▪ Funding policy.</li><li>▪ All of barriers = funding/workforce culture (silo mentality).</li></ul>
Child & Adolescent Neurology - Transition to Adult Services	<ul style="list-style-type: none"><li>▪ Child Neurology &amp; Adolescent Neurology.<ul style="list-style-type: none"><li>i. Funding/staffing/workforce issues. Resource utilisation most effective, size of task(s) being undertaken.</li><li>ii. Geography/population growth/population diversity.</li><li>iii. Engaging all stakeholders appropriately. Availability and interest and preparedness of primary carer and community.</li><li>iv. Legal issues.</li></ul></li></ul>



## Enablers Identified

Table 2: Enablers identified by broad category

Broad Category	Barriers Identified
Workforce	<ul style="list-style-type: none"><li>▪ Manpower/workforce.<ul style="list-style-type: none"><li>i. Better planning (see <a href="#">Healthy Workforce Strategic Framework 2006 - 2016</a>)</li><li>ii. Links with training institutes.</li><li>iii. Better communication across areas (eg: health services, workforce planning, Department &amp; SMAHS).</li><li>iv. Decreased silos.</li><li>v. Ability to consider alternative models for service delivery - travelling teams/access to education/funding.</li><li>vi. Career structure.</li></ul></li><li>▪ Desire, motivation and goodwill.</li><li>▪ Champions.</li><li>▪ Sharing expertise.</li><li>▪ Facilitating private providers/specialists to work in the public system.</li><li>▪ Remove 'closed shop' mentality of teaching centres (Universities) and remote barriers to overseas specialists working in WA.<ul style="list-style-type: none"><li>i. Care managers/case managers.</li><li>ii. With clear guidelines for the role.</li><li>iii. Systems assistance with process → triaging services.</li><li>iv. Increase networks</li></ul></li><li>▪ Increased access to specialist rehabilitation services → network of specialty services.<ul style="list-style-type: none"><li>i. Specialist trained staff at community services.</li></ul></li><li>▪ The Princess Margaret Hospital Cochlear Implant Speech Pathologists have made excellent links with WAIDE teachers of the deaf and with Speech Pathologists in Country areas. This has resulted in the</li></ul>



	<p>provision of specialist workshops via teleconferencing and the establishing of a regular interest group with WAIDE teachers of the Deaf.</p> <ul style="list-style-type: none"> <li>▪ The PMH library provides excellent support to all staff including Allied Health and a range of strategies are in place to support their access to research literature to enhance evidence based practice (Permanent Search Topics and Alerts, Table of Contents Alerts, regular skills updates).</li> <li>▪ The Child &amp; Adolescent Health Service Intranet and WA Country Health Service intranets provide an excellent forum for sharing skills, knowledge and resources.</li> <li>▪ There are a number of forums and interest groups attended by allied health members to share skills, knowledge and develop new models of care.</li> </ul>
Models of Care or Care Aspects	<ul style="list-style-type: none"> <li>▪ Consumer representation on Models of Care.             <ul style="list-style-type: none"> <li>i. Health Networks have acknowledged value.</li> <li>ii. Travel allowance/financial support.</li> <li>iii. Proactive seeking of consumer input.</li> <li>iv. Advertising.</li> </ul> </li> <li>▪ Identifying need for increased services in community.             <ul style="list-style-type: none"> <li>i. Resource re-allocation (money/workforce).</li> <li>ii. Equity for regions.</li> <li>iii. Alternative funding sources.</li> </ul> </li> <li>▪ Rural access.             <ul style="list-style-type: none"> <li>i. Telehealth - needs to be more accessible.</li> <li>ii. Helps with deciding who needs tertiary care.</li> <li>iii. Able to provide support/education to rural practitioners.</li> </ul> </li> </ul>
Education and Research	<ul style="list-style-type: none"> <li>▪ Demonstrate progress and feasibility - ie: Swan Districts Hospital Stroke Unit.</li> </ul>



	<ul style="list-style-type: none"><li>▪ University specialist training is provided on understanding that graduates will service regional/wider areas and secondary health facilities.</li><li>▪ Each model of care/priority should link to/be informed by research.</li><li>▪ Improved access to information across different health care providers/agencies.</li><li>▪ Education and ongoing development.</li><li>▪ The PMH Speech Pathology Department has allocated a small proportion of time (0.2) for the purpose of supporting a rotating clinical research position.</li></ul>
Continuity of Care Delivery	<ul style="list-style-type: none"><li>▪ Consolidation &amp; rationalisation of health and disability service delivered by government and non-government agencies.</li><li>▪ Inter-government cooperation (department). Commonwealth vs. State.</li><li>▪ Incentives for collaboration between primary, secondary health care and NGOs (referral, information sharing, joint programs etc).</li><li>▪ Increased private care - (funding?) and allied health.</li><li>▪ Policy change.</li><li>▪ Services.<ul style="list-style-type: none"><li>i. Case management improves service integration.</li><li>ii. Preparing directories of available services/making these widely available.</li><li>iii. Health Networks - able to share information.</li></ul></li><li>▪ The Western Australian Country Health Service provide support to children with Cochlear Implant living in rural areas and are able to liaise effectively with the PMH team to provide a model of care which reflects a continuum from acute tertiary to community services for children in rural areas.</li><li>▪ Skilled/caring professionals, technology.</li></ul>



Commonwealth and State Funding	<ul style="list-style-type: none"><li>▪ Extra funding - could be an enabler.</li><li>▪ Disability Services Commission funding.</li></ul>
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### *Individual Reflection*

The aim of the individual reflection was to gain an understanding of how the Neurosciences & the Senses Health Network can improve its engagement with key stakeholders. The rationale is that better engagement will result in more effective business for the Network.

The participants were provided with two questions for their individual reflection; 'How can this Network better meet your needs' and 'How can this Network better meet the needs of your area/field'. The responses received can be organised into several key categories.

Broadly, the resulting categories were organised in the following (a comprehensive list of comments is provided in **appendix 2**):

1. Communication
2. Collaboration/ Networking
3. Consultation/ Engagement
4. Data/Research
5. Workforce/ Resources
6. Services
7. Funding

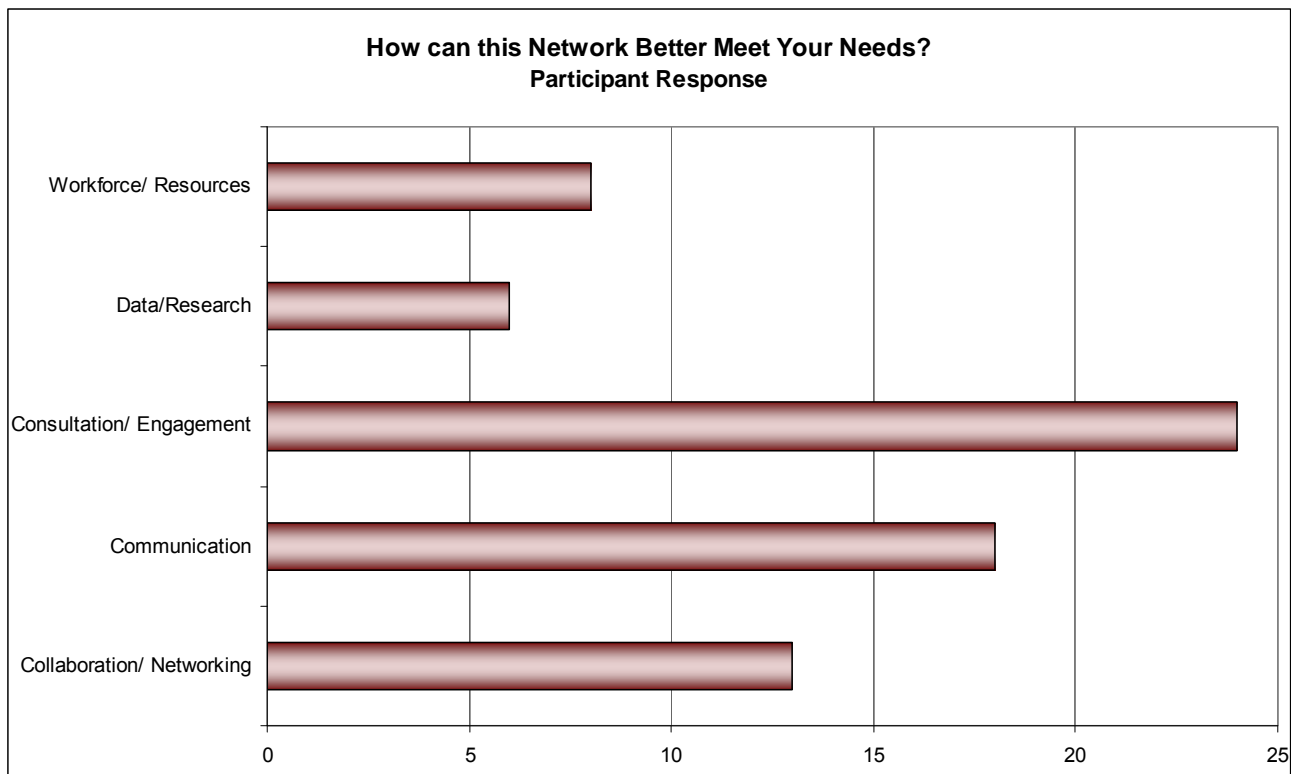
NOTE: The categories are represented in the responses from both questions.

For the question 'How can this Network better meet your needs?' participants provided 69 responses of which the majority related to Consultation/ Engagement on the Network business and initiatives, followed by comments on Communication.

Total response results are represented in **Figure 2**.



**Figure 2:** How can this Network better meet your needs? Participant responses organised into broad categories.

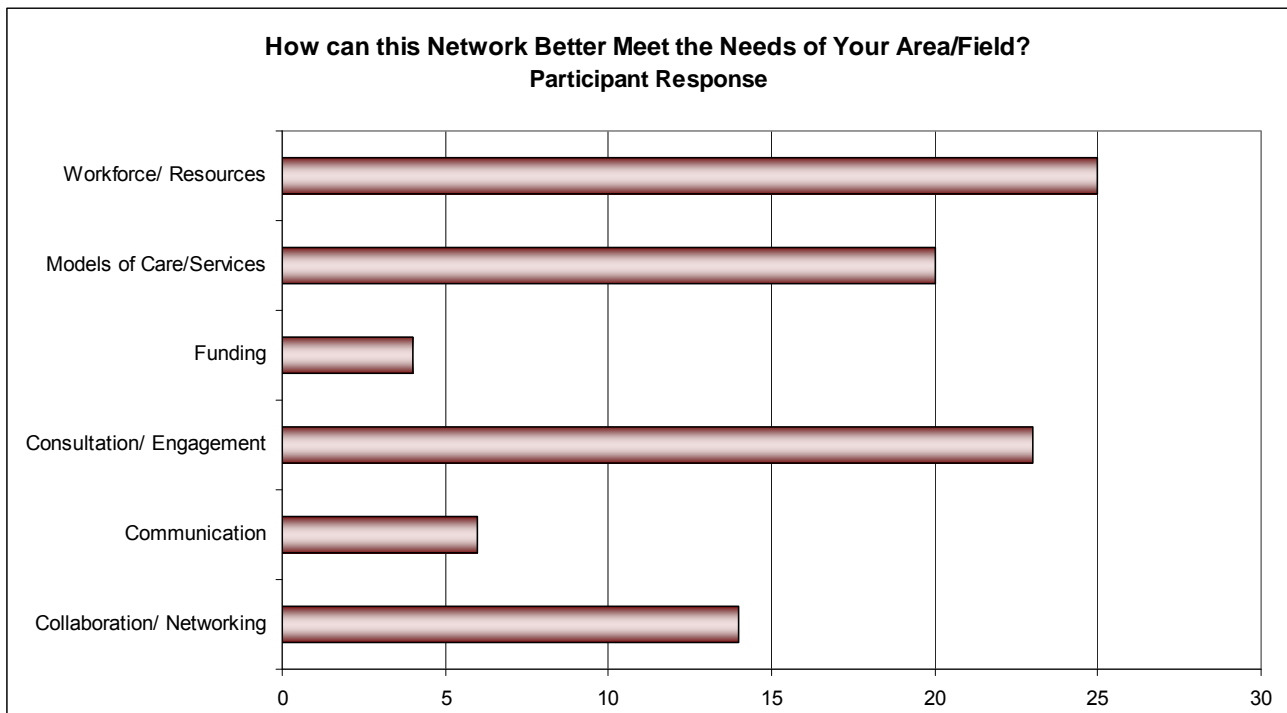


When asked to reflect on ‘How can this Network better meet the needs of your area/field?’ participants provided 93 responses of which the majority related to Workforce/Resources followed closely by comments on Consultation/ Engagement.

Total response results are represented in Figure 3.



**Figure 3:** How can this Network better meet the needs of your area/field?  
Participant responses organised into broad categories.



## 4. DISCUSSION

A few specific conditions were identified during discussions held at individual tables and these included:

1. Motor Neurone Disease
2. Neural Deafness
3. Parkinson's Disease

Additionally, participants identified the transition of care for children and adolescents to adult services to be a high priority.

### 4.1 Motor Neurone Disease

The Motor Neurone Disease Project Group, a subgroup to the Neurosciences & the Senses Health Network, has developed a draft model of care *Motor Neurone Disease Services for Western Australia*. The draft model sets out a strategic and coordinated approach to Motor Neurone Disease services and builds on the strengths of existing services while addressing the gaps. The draft model of care has been developed by a group of key stakeholders across the acute and community health care sectors.



## 4.2 Neural Deafness

The Neural Deafness Project Group is a recently established subgroup to the Network. This group will develop a model of care to address a coordinated approach for this condition.

## 4.3 Parkinson's Disease

The Aged Care Health Network has developed a draft service delivery model of care, *Parkinson's Disease Services Model of Care for the Older Person in WA*. The draft is available for information on the Health Networks website. <http://www.healthnetworks.health.wa.gov.au/agedcare/moc.cfm>

## 4.4 Transition of Care for Children and Adolescents

The Child and Youth Health Network is developing a draft framework, *The Transition Framework*. The draft will be available for stakeholder consultation in 2008.

## 5. CONCLUSION

The Neurosciences & the Senses Health Network (NSHN) business for 2008/2009 will be driven by the results of this stakeholder forum.

It is evident that the priorities for the key stakeholders representing the disciplines included in the NSHN have now focused more on areas of wide impact across the sector, rather than priority conditions. This does not exclude conditions from the work of the Network but rather re-directs its focus to underlying system issues.

## 6. EVALUATION

Attendees were asked to review the Forum and fill out an evaluation form. The results have been analysed and are provided in **appendix 3**.



## 7. APPENDICES

### Appendix 1 - Scribed Table Discussions

#### Table 1

##### *Identify & Discuss New Priorities*

- Consumer representation on Models of Care.
- Greater involvement of care workers (multidisciplinary) who implement the services, leading to increased services.
- Modelling the shift from 3° to 2° to community (in terms of services and workforce).
- Better promotion of health as a career option (pathways from school).
- Identifying need for increased services in community.
- Manpower/workforce.
- Telehealth.
- Supporting staff (rural & metro) - mentoring roles.

##### *Barriers for the Top 3 Priorities*

1. Consumer representation on Models.
  - i. 3° centric models.
  - ii. Doctor centric models.
  - iii. Funding for change/models of care.
  - iv. Closing the gaps in lack of services in community.

##### *Enablers for the Top 3 Priorities*

1. Consumer representation on Models of Care.
  - i. Health Networks have acknowledged value.
  - ii. Travel allowance/financial support.
  - iii. Proactive seeking of consumer input.
  - iv. Advertising.
2. Identifying need for increased services in community.
  - i. Resource re-allocation (money/workforce).
  - ii. Equity for regions.
  - iii. Alternative funding sources.



3. Manpower/workforce.
  - i. Better planning (see workforce planning paper 2006)
  - ii. Links with training institutes.
  - iii. Better communication across areas (eg: health services, workforce planning, Department & SMAHS).
  - iv. Decreased silos.
  - v. Ability to consider alternative models for service delivery - travelling teams/access to education/funding.
  - vi. Career structure.

## Table 2

### *Identify & Discuss New Priorities*

- Consolidation & rationalisation of health & disability. Services delivered by government and NGO agencies.
- Education/research on area of Neurosciences for community.
- Training program for doctors, nurses, allied health.
- New funding to implement changes etc (lobby immediately).
- Commonwealth funding - initiatives to access private sector on greater level to reduce (eg. Specialist fee reduction/health care plans).
- Education of community, GPs etc of initiatives. (Reactive and needs to be proactive)
- New funding:
  - Trainee nurses/doctors/allied health.
  - To implement changes.
  - Implement Health Care Plans.
  - To meet unmet demand in care & research.
- DSC Health & others.
  - Communication/cooperative service delivery, eg: COASG, CSDP.
- Residential care model helpline for people with neurological/disability to reduce admissions (ie: including families at home having access)
- Map services (little & big) and work out how to simplify delivery/funding.
- Baseline funding for NGOs to assist with community delivery of care (eg: secondment - competitive).
- Continuity of care (delivery):
  - DSC/Health transitions
  - Prevention
  - NGOs



### *Enablers for the Top 3 Priorities*

1. Consolidation & rationalisation of health and disability service delivered by government and non-government agencies.
2. Inter-government cooperation (department). Commonwealth vs. State.

### Table 5

### *Identify & Discuss New Priorities*

(Table 5 stated that they had difficulty identifying 3 priorities)

- Treatment not adequately stressed. The treatment aspect is important - not adequately stressed. Coordination model of ABI/Stroke:
  - Pathway
  - Respite
  - 2° level care
  - Community level
  - 3°/4° level
- Try to establish a model that can be applied across most neurological disorders.
- “Network” across conditions to maximise resource utilisation to cover rarer & special conditions as well as more common issues.
- Child Neurology & Adolescent Neurology.
- Funding.

### *Barriers for the Top 3 Priorities*

3. Treatment not adequately stressed.
4. Not to limit to specific areas. Lots of areas “worthy” priorities.
5. Child Neurology & Adolescent Neurology.
  - i. Funding/staffing/workforce issues. Resource utilisation most effective, size of task(s) being undertaken.
  - ii. Geography/population growth/population diversity.
  - iii. Engaging all stakeholders appropriately. Availability and interest and preparedness of primary carer and community.
  - iv. Legal issues.

### *Enablers for the Top 3 Priorities*

1. Desire, motivation and goodwill.
2. Champions



3. Extra funding - could be an enabler
4. Demonstrate progress and feasibility - ie: Swan Districts Hospital Stroke Unit.

### Table 6

#### *Identify & Discuss New Priorities*

- Methodology will be flawed if it doesn't address turf barriers (Referral processes - primary assessment/care & Long term ongoing support):
  - Federal
  - State
  - Departments
  - Locations
  - Aged/Health etc.
- Resourcing and the practical implementation of a de-centralised strategy. Strategic theory vs. practical application.
- Neurodegeneration - identified but what is the work in progress?

#### *Enablers for the Top 3 Priorities*

1. University specialist training is provided on understanding that graduates will service regional/wider areas and secondary health facilities.
2. Facilitating private providers/specialists to work in the public system.
3. Remove 'closed shop' mentality of teaching centres (Universities) and remote barriers to overseas specialists working in WA.
4. Each model of care/priority should link to/be informed by research.
5. Improved access to information across different health care providers/agencies.
6. Incentives for collaboration between primary, secondary health care and NGOs (referral, information sharing, joint programs etc).

### Table 7

#### *Identify & Discuss New Priorities*

- Rehabilitation care and current model.
  - Aged Care divide >65 years/<65 years.
  - DSC
  - Access
- End of life management.
  - Links
  - Facilities



- Not just 60 days
- Workforce
  - Sub-specialty vs. general training
  - Linkages
- Models of Care
  - Extended to Community Care
  - i.e.: Vision loss rehabilitation

### *Barriers for the Top 3 Priorities*

1. Gate keeping.
2. Funding policy.

### *Enablers for the Top 3 Priorities*

1. Increased private care - (funding?) and allied health.
2. Education and ongoing development.
3. Sharing expertise.
4. Policy change.
5. DSC funding.

### **Table 8**

#### *Identify & Discuss New Priorities*

(Needs based)

- Outpatient services for <65 years. Discharge from acute to community.
  - Gaps: ABI secondary cancer, spinal, any Neuro condition.
  - Services: Rehabilitation (inpatient/outpatient/at home), Respite (appropriate and timely)
- Long term accommodation for <65 years i.e.: age appropriate.
  - Tracheostomy care
  - Severe ABI
- MND services. Recognition of need for prompt appropriate care needs
  - Carer funding
  - Community services (EACH)
  - Fast track referrals
  - CAEP equipment (federal funding)
  - Early introduction of Palliative Care Services



- Accessing DSC for all services for <65 years.
- Formal carer education.
  - Disease specific but generic skills.

### *Barriers for the Top 3 Priorities*

1. Lack of needs based access <65.
2. Lack of carer support
  - i. Education
  - ii. Rehabilitation
  - iii. Respite (appropriate facilities)

### *Enablers for the Top 3 Priorities*

1. Care managers/case managers.
  - i. With clear guidelines for the role.
  - ii. Systems assistance with process → triaging services.
  - iii. Increase networks
2. Increased access to specialist rehabilitation services → network of specialty services.
  - i. i.e.: Specialist trained staff at community services.

## Table 9

### *Identify & Discuss New Priorities*

- Residential care for young disabled.
- Ongoing multidisciplinary rehabilitation for younger (<65) people with ABI. Services are mostly day hospital models designed for aged care settings.
- Transition of young people with chronic neuro conditions to adult care.
- Prevention - strategies to prevent/reduce TBI (Traumatic Brain Injury?). Education of communities/school age.
- Epilepsy (especially in paediatrics) - management of co-morbidities, especially intellectual disability.
- Respite care for chronic neurological conditions (especially for severe complex cases). Difficulty is such that respite becomes a crisis situation/serious mental health issues for carer.
- Management of funding via DSC.
- Therapy services outside metro area.
- Parkinsons - better management of early stages. Services currently very regionalised. Very little available away from OPH/Moss St.
- Services for young Parkinsons Disease patients.



### ***Top 3 Priorities***

- Services (including respite) for people <65 with neurological conditions.
  - Residential care
  - Transition
  - Therapy (ongoing access)
  - Funding models
- Availability of services outside of Metro areas. Long term need to consider building up rural services.
- Prevention of ABI.
  - Education - expansion of current programs.
  - Monitoring of preventable risks.
  - Other accident risk reduction.

### ***Barriers for the Top 3 Priorities***

(All of them = funding/workforce culture (silo mentality))

1. Services (including respite).
  - i. Currently very fragmented & have different access criteria.
  - ii. Lack of directories of available services.
  - iii. Interaction between agencies and integration between housing/ education/ health services.
2. Rural access.
  - i. Very hard to service whole of WA.
  - ii. Some services do need high level of skill (inappropriate for primary settings).
  - iii. Lack of support for clinicians to get experience in rural areas.
  - iv. Lack of support for rural practitioners (though Telehealth can assist with this).
  - v. Special needs of particular areas.
  - vi. "Turf Protection".
3. Peer group appropriate models of education.
  - i. Hard to demonstrate success of prevention/measure outcomes (epidemiological data/population health)

### ***Enablers for the Top 3 Priorities***

1. Services.
  - i. Case management improves service integration.



- ii. Preparing directories of available services/making these widely available.
  - iii. Health Networks - able to share information.
2. Rural access.
- i. Telehealth - needs to be more accessible.
  - ii. Helps with deciding who needs tertiary care.
  - iii. Able to provide support/education to rural practitioners.

### Additional Input

(Additional feedback was received via email 27 March 2008)

### *Identify & Discuss New Priorities*

(Priorities are given from a PMH Speech Pathology Department and Allied Health perspective.)

- Provision of a coordinated model of care for children with Neural Deafness.
- Provision of a coordinated model of care for children with Neurogenic disorders including ABI and Epilepsy, resulting in communication and feeding impairments.
- Conduct clinical research to identify the most effective means of achieving positive therapy outcomes for children with Neurogenic Communication, Feeding and Hearing impairments.
- Neural deafness - establishing co-ordinated model of care including diagnosis, assistive devices (incl hearing aids and cochlear implants) with habilitation, educational/vocational support and regular monitoring.

### *Barriers for the Top 3 Priorities*

1. The key barrier to effective provision of a Model of Care which is coordinated with community services is the lack of access to community services themselves.
2. The community Speech Pathology services funded by DSC are often able to accept referrals for these children [children with other Neurogenic communication disorders - Epilepsy, ABI] for their ongoing needs, there is often a long waitlist for services, which results in families accessing tertiary level services for longer than ideal.
3. Transitioning children with Neurogenic communication and feeding disorders to local community services can be made more difficult when those services do not have the skills or knowledge to manage more complex cases.
4. Available time and funding to commence research. Curtin University students are currently able to engage in Speech Pathology Department QA activities under supervision. The University has not yet developed a stream for Speech Pathology students to engage with teaching hospitals in joint in clinical research as part of their undergraduate placement training.



5. Integration of several agencies (who does what when and where?), distribution of resources, physical location of services.

### *Enablers for the Top 3 Priorities*

1. The Western Australian Country Health Service, do provide support to children with Cochlear Implant living in rural areas and are able to liaise effectively with the PMH team to provide a model of care which reflects a continuum from acute tertiary to community services for children in rural areas.
2. The PMH Cochlear Implant Speech Pathologists have made excellent links with WAIDE teachers of the deaf and with Speech Pathologists in Country areas. This has resulted in the provision of specialist workshops via teleconferencing and the establishing of a regular interest group with WAIDE teachers of the Deaf.
3. The PMH library provides excellent support to all staff including Allied Health and a range of strategies are in place to support their access to research literature to enhance EBP (Permanent Search Topics and Alerts, Table of Contents Alerts, regular skills updates).
4. The CAHS Intranet and WACHS intranets provide an excellent forum for sharing skills, knowledge and resources.
5. There are a number of forums and interest groups attended by allied health members to share skills, knowledge and develop new models of care.
6. The PMH Speech Pathology Department has allocated a small proportion of time (0.2) for the purpose of supporting a rotating clinical research position.
7. Skilled/caring professionals, technology.



## Appendix 2 - Scribed Individual Reflection

### Individual Reflection

#### *How Can This Network Better Meet Your Needs?*

- Facilitate consultation between NGOs providing services in this area.
- Work closely with other Health Networks eg: Aged Care.
- More specific information on what is being worked on & how/who to talk to/link into (as is happening).
- Indication of lines of communication.
- List of people involved in Network & area/position working in (including information on point of contact).
- Focus on staff retention ie: recognition that ACAT workloads have become unmanageable.
- Greater access to training opportunities.
- Resources/tools to work - not enough vehicles or computers to provide the service.
- Shorter meetings.
- Focus groups for area & specialty
- Collaboration with wider group.
- To expand the structure of the Network to allow more active participation in the development of Models.
- Improve the feedback systems - no minutes received from the 1<sup>st</sup> stakeholders meeting.
- Knowledge of process/progress of Network ie: what's been done so far?
- Future directions/goal planning in the next phase of health reform.
- Offering me opportunity to contribute.
- I work across a number of areas within the Network and would value the opportunity to contribute to more than just the ABI area.
- I would like to have more opportunity to interact with contributors from the Network at my actual work level, not just in forums.
- (Physiotherapist) Development of peripheral & rural centres and their ability to treat neurological conditions. This would promote these hospitals/services as attractive places to work as an Allied Health member, assisting in attracting staff. This would require improved PD opportunities and support from specialised clinicians.
- To assist in better servicing the ABI population in this State. To assist them to achieve better outcomes and ultimately a better quality of life. This will give me better job satisfaction.



- Ongoing wide consultation.
- Email updates on what is currently in development and regular progress.
- Continued focus on development of non-tertiary services.
- I am a physiotherapist working in Aged Care rehabilitation setting. I hoped involvement in Network would increase my awareness of plans for future services & details of content for such services - frequent, accessible information with regards to this would help.
- Ways of disseminating information coming out of Networks to those working outside Health (Academic but very interested in Health Reform - don't get routine access to DoH information).
- Need to link education/training with health provision.
- Feel valued.
- My opinion counts.
- Forum as an important way in networking with stakeholders.
- Referral pathways in stroke inpatient/outpatient clinics.
- Be given priorities & summary information from previous Network forums/meeting prior to today's Forum.
- More often → rather than annually (?) to share new ideas and feedback to progress in developing the Network.
- More networking with specific/own disciplines to increase knowledge of what is happening in other hospitals/community organisations.
- Having more information provided before the Forum so I would be able to reflect more fully, especially on areas my input is requested.
- More information on what is happening currently and in the future and how to get involved. Could then apply skills from the area & also promote the field.
- Network may, with additional support, be able to advance epidemiological & data structure so that we are all working from a more informed basics.
- Perhaps by delivering Epidemiological bulletins.
- Regular communication of what progress is being made.
- Allow feedback in groups of clinical areas → to be more useful in directing working group actions.
- Better understanding of the development & progress of the Network required.
- More meetings/networking → progress meetings.
- Little opportunity to contribute re: special areas of expertise & interest (Eye Health/Consumer Focus).
- Need to meet more frequently than 1 in 2 years.
- Need to cluster conversations in areas of expertise - a lot of expertise in the room not taken advantage of.
- Will seek involvement in EAG & Eye Health Working Group.



- Recognise that the needs for a child & adolescent with neurological disorders may not always be the same as an adult or elderly person.
- Listen to us & involve us in planning.
- It would be useful if some forward projections, using demographic/workforce information could be made available, so that we can sense what the world might look like in 10-15 years time and how our areas of interest fit into the revised community structures.
- (Neurogenetics) Integration of research into each model of care.
- Increased communication re; initiatives in progress.
- Working group within NSHN on Dementia.
- Representative on EAG with Dementia expertise.
- Parking.
- Train more Neuro people. More ???
- Research - each model of care/priority should be linked (ort confirmed by) research.
- Alzheimer's should be in Neurosciences.
- Network/link between primary assessment/treatment & those involved in long-term/ageing support.
- Predict demographics → Neuro-degeneration & Stroke will be where the old people are.
- Regular (brief/executive summary) updates of goals and work in progress.
- Increased access to developments of working group - opportunities to comment on policy changes in draft form, before these changes are set in concrete.
- (Allied Health) I would like to hear more initiatives/functional changes that will directly improve patient care that can be acted on in the short term. Perhaps the attendees' diversity decreases this.
- I'd like to see leadership from the Network in addressing workforce models that shift patient care from the tertiary sector to the secondary hospital sites eg: co-appointments, rotational positions, travelling consultant clinics etc.
- (Allied Health) More consultation on setting up of working groups for broader representation.
- (Allied Health) Ongoing input for development of models of care & implementation phase.
- May be worthwhile sharing some separate forums for Neurosciences & for the Senses (too broad and different issues).
- Too much emphasis on Neurosciences.
- Need a committee to support Eye Health Plan - currently only 1 person.
- Alzheimer's Centre for Research & Care represents researchers from all the major WA Universities and 2 aged care providers - Hall & Prior and Anglical



Homes. A representative from this WA Alzheimer's Centre should be included on Dr Goldswain's Alzheimer's Committee.

- Listen to what we need first rather than state directed.
- Recognise Paediatric Neurology (child & adolescent) as an area of special expertise.

#### *How Can This Network Better Meet the Needs of Your Area/Field?*

- Better support the work of the NGO sector by finding ways to attract new funding.
- Foster collaboration and consolidation of service provision across the health and disability sector.
- Be flexible in trying to reduce unmet needs in the neuro sector.
- Increase the education and research opportunities for the neuro sector to better manage the increasing demand for services.
- Find the implementation phase of models of care with some extra funding.
- Foster Commonwealth/State relations to improve outcomes for clients.
- Improved educational services.
- Increase nurse specialists.
- Commence government funding.
- Provide accommodation for remote and rural when visiting Perth for appointments.
- Initiate common ground for future synergies both NGO and professional services.
- Recognition of diversity of types and age of those affected (including family and carers),
- Lobbying state/federal government (collectively has better potential of success).
- Interaction with other NGO's and Professionals.
- Paediatric (import of early diagnosis relates to education and helpline.
- DCS and Health department
- Remote and rural/indigenous communities.
- Increase in O/A servicing provided (currently).
- Recognise the input provided by NGO's - not just assumed input.
- Provide clear pathways for access to services for under and over 65 year olds eg DHWA /DSC etc.
- Increase understanding (education of health professionals).
- Look long and hard at neurodegenerative conditions beyond Alzheimer's delivery and reduce patient costs ie Huntington's Disease and others that need



treatments/health services models applied that don't have currently eg Allied health services/pain management care physio, OT, dieticians.

- Increased services for over 65 years of age appropriate and travelling access to residential and in-home respite programs.
- Care coordination/case management service for MND patients. ACATS are unable to provide the intensive ongoing support that is needed.
- Cancer: Increased culegration and collaboration with cancer network.
- Access to coordination for neuro and patients.
- MOC: epilepsy: Collaboration with cancer network for pts with tumour induced epilepsy.
- CVA: Collaboration with cancer network for pts with ABI 2° to tumour or subsequent surgery.
- Rehab/respite/continuing care for over 65 year olds.
- Palliative care: Inclusions of death/dying in the models developed.
- Communication/carer education.
- Advanced Care Planning.
- Hydration nutrition.
- Referral to specialist service if needed of patient/carer exceed capabilities of treating team.
- Acute Neurology: Continue to address funding to increase rehab workforce.
- OT: Allied Health involvement on committees - this may be by having more AH feedback on draft documents.
- Professional: Ensuring the network acknowledges the need for and needs of the Allied Health Services. (I think it does this but needed to reinforce the concepts).
- Continue to acknowledge and include input from service providers outside of the immediate hospital system - community providers.
- Support an improved understanding of the importance of health within a well being framework with the disability sector.
- Acknowledge that for most people with neurological disability ABI, stroke neurodegeneration the largest part of their life happens outside the hospital.
- Improvement in respite care facilities and transition arrangements from child and adolescent services to adult services.
- Provision of adequate workforce to enable work to be done in a timely manner.
- Physiotherapy: Lobby for increased utilisation of 2° and community services to improve patient outcomes and therapy staff satisfaction.
- Increase clinician support for early discharge/transfer from 3° to 2° hospitals.
- Increase therapy clinician involvement/representation in Health Network and on committees/advisory groups.



- Lobby for extended scope approval for physios/allied health especially in rural areas.
- To provide a more coordinated approach to caring for the neuro patient from admission to care in the community.
- Continued wide consultation. We provide services to adults in CD (including ABHI, strokes PD) but were never invited to comment or input into stroke, ABHI or PD models of care. Didn't even know they were being developed. I feel this will be to the detriment of the WA Health Service and clients. (Partly due to silo mentality).
- Continued forums for discussion be held with health professionals across many services and NGO and consumers.
- As a physiotherapist, what do these models of care mean to me and what I have to do? Dissemination of info
- Dissemination of info via our professional body or a 'champion' of neuro physio across the network?? To provide specific info this may apply to each area represented.
- Need to engage "up and coming" AHPs not just seniors.
- Need to address training needs (informal and formal) to prepare workforce for diversified service.
- Need to engage consumers more.
- To know that real issues are acknowledged and are being addressed.
- That the network represents the pts. Needs and improve outcomes.
- Invite more dietetic representatives - clinical/community and rural dietitians.
- Improved communications/consultation and education between sites that may be more specialised in neuro related treatment.
- More perspective from community/NGD/DSC etc rather than hospital focus - to know the extent of their resources/ability to affect change in neuro/senses.
- Nursing needs higher profile and representation on network - workforce issues in this group are critical.
- Better engagement of metropolitan area health services needs to occur.
- Valuable to network and talk with diverse group.
- Further encourage input from those working at the "coal face" as well as Pd consumer input.
- Actively seek consumer input.
- Neuro newsletter.
- Efforts to advance resource allocation for this needy patient group.
- Can be better met by ensuring that the push is move responsibility for care by 1° health (GPs) is widely accepted by those stakeholders.



- Encourage /foster and value diverse attendance ie from GPs/2° hospitals/community to provide a variety of opinion and draw them into development process.
- Increased progress meetings (at least yearly) so theme of process does not get forgotten.
- Contact details of network members made available for collaboration increase push for secondary hospitals to attend/be involved as they are largely affected by this change.
- Participated one very brief and inadequate meeting in 2006 on the Eye Health Plan. Heard nothing since. Would like to participate in Eye Health Group and have much more conversation/involvement in Eye Health.
- Very strong links between Eye Health and macular degeneration.
- Aged care and Falls. Our organisation should also probably be represented on both these networks.
- Recognise paediatric and adult neurology as an art of special expertise.
- Provide for funding for paediatric neurology training.
- Provide for multidisciplinary care for children and adult problems increase adequate administrative support.
- ABI: It would be useful if a representative ABI group emerged in line in the case coordination model, as such a group doesn't formally exist.
- Actively feeding appropriate patients from other neurologists into the neurogenic unit at RPH directed by Phillipa Lamont.
- Back up in terms of appropriately trained neurogenetic neurologist for Phillipa Lamont.
- Increased emphasis on dementia as a neurological issue rather than aged care (eg rapidly increasing early onset diagnosis 40s and 50s).
- UWA trains Clinical Neurologists but at this stage the career path for the graduates needs clear definition/presence within the Health Department.
- UWA also trains industrial and organisational psychologists skilled in job design and organisational change - these people could advise on implementation of models of care - cont David Morrison 64883246.
- Greater engagement of relevant NGOs in process.
- Professional Reflection: Increased involvement in policy development. Working groups on the whole are medico-centric and have few allied health/on the ground care providers. This is especially true of the ABI working group. Groups appear to have been formed from "old" and established networks.
- Ongoing open contact between clinicians and networks. There seems to be a distinct group - support for training and development to initiate basic level workplace planning.
- The network can take a lead role in managing up the importance of transition of RPH/SPC to a state rehab centre and the importance of early location of that Fv from Shenton Park to the Fiona Stanley Campus.



- The state rehab centre concept is integral to the management of neurosciences and the senses patients and needs to be put on the agenda in terms of finding/role and location. Access in/transfers out and continuum of care etc.
- Professional refleche - Allied Health. Recognising need for career development, access to training, experience, and education in specialty areas.
- Role of many Allied Health often covers many areas so need to consider this in service planning, workforce planning and retention of staff.
- Process for identifying priorities very difficult - many consider targeting participants from similar backgrounds together.
- Consultation with development of Eye Health plan very limited this needs to be addressed. Needs to include extending models of care beyond specialist input.
- Alzheimer Care Centre for research and care represents researchers from all the major WA universities and 2 aged CCU provides Hall and Pryer and Anglican Homes. A representative from this WA Alzheimer Centre should be included in Dr Goldswain's Alzheimer committee.
- Provide for training in paediatric/newborns - currently no regular finding.
- Include AHS, Deaf Society, WAIDE and Tsp&H in network.
- Develop a Model of Care for WA Cochlear Implant Service.



### Appendix 3 - Evaluation Results

#### Q1.1 I feel I was able to contribute to the Forum

	Valid Percent
Strongly agree	9.1
Agree	72.7
Neutral	15.2
Disagree	3.0
Total	100.0

#### Q1.2 I feel my contribution to the Forum was valued

	Valid Percent
Strongly agree	6.1
Agree	63.6
Neutral	27.3
Disagree	3.0
Total	100.0

#### Q1.3 Attendance at the Forum was a valuable use of my time

	Valid Percent
Strongly agree	12.1
Agree	63.6
Neutral	15.2
Disagree	6.1
Strongly disagree	3.0
Total	100.0



**Q4. What did you value least about the Neurosciences and the Senses Health Network Stakeholder Forum**

	Responses		Percent of Cases
	N	Percent	
Dynamics of the group discussion session	4	16.70%	21.10%
Lack of a seating plan	4	16.70%	21.10%
More time needed to reach agreement and/or break down 'silos'	2	8.30%	10.50%
Discussion session lacked sufficient structure	2	8.30%	10.50%
Unsure of the aim of the group discussion	1	4.20%	5.30%
Uncertain about the 'way forward'	1	4.20%	5.30%
Limited time and opportunity to make a meaningful contribution	1	4.20%	5.30%
Not enough information about or introduction of attendees	1	4.20%	5.30%
Insufficient emphasis on next steps or way forward	1	4.20%	5.30%
Insufficient consultation on the 'eye plan'	1	4.20%	5.30%
Insufficient pre-forum instruction/brief for attendees	1	4.20%	5.30%
Limited time to collaborate/make use of expertise	1	4.20%	5.30%
Tertiary sector overrepresented	1	4.20%	5.30%
Lack of ongoing engagement with broader stakeholder groups	1	4.20%	5.30%
Catering	1	4.20%	5.30%
Lack of ABHI representation	1	4.20%	5.30%
<b>Total</b>	<b>24</b>	<b>100.0%</b>	<b>126.3%</b>

**Multiple Response Table**



**Q5. What could be done to improve the Neurosciences and the Senses Health Network Stakeholder Forum?**

	Responses		Percent of Cases
	N	Percent	
More frequent communication and engagement with a broad range of stakeholders	8	21.60%	28.60%
Events to occur more frequently	6	16.20%	21.40%
Improved catering	3	8.10%	10.70%
Develop concrete timelines and goals	3	8.10%	10.70%
Wider representation especially from the non-tertiary sector	2	5.40%	7.10%
More pre-event instruction/preparation	2	5.40%	7.10%
Smaller care groups	1	2.70%	3.60%
Use outcomes to direct working groups	1	2.70%	3.60%
Increase the font size on presentations	1	2.70%	3.60%
A panel session of speakers to explore issues	1	2.70%	3.60%
Next event to build on issues and priorities identified today	1	2.70%	3.60%
Include broader representation on the EAG	1	2.70%	3.60%
Have a seating plan	1	2.70%	3.60%
Collect and make use of group discussion notes	1	2.70%	3.60%
Change event timing away from the Easter period	1	2.70%	3.60%
Focus more on commonalities rather than differences between groups	1	2.70%	3.60%
Discuss progress since last event	1	2.70%	3.60%
Change event methodology- open space technology	1	2.70%	3.60%
Future Forums to build on identified priorities	1	2.70%	3.60%
<b>Total</b>	<b>37</b>	<b>100.0%</b>	<b>132.1%</b>

**Multiple Response Table**



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