Care pathways for people with neurodegenerative and neuromuscular conditions

Action areas for consideration by ACI Networks

ACI Neurodegenerative and Neuromuscular Conditions Working Group
The Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this through:

- **service redesign and evaluation** – applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services.

- **specialist advice on healthcare innovation** – advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment.

- **initiatives including Guidelines and Models of Care** – developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system.

- **implementation support** – working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW.

- **knowledge sharing** – partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement.

- **continuous capability building** – working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations.

A key priority for the ACI is identifying unwarranted variation in clinical practice. ACI teams work in partnership with healthcare providers to develop mechanisms aimed at reducing unwarranted variation and improving clinical practice and patient care.

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Section 1

Executive summary

There are many different types of neurodegenerative (ND) and neuromuscular (NM) conditions that individually are quite rare, but collectively affect many people. These conditions have a significant impact and cost on individuals, their carers and communities, and the Australian health system.

This document represents the next stage in a significant body of work supported by the NSW Agency of Clinical Innovation (ACI) that aims to improve outcomes for people with neurodegenerative and neuromuscular conditions. A Neurodegenerative and Neuromuscular Conditions Working Group has been working together since July 2014 to identify needs, develop a case for change and identify areas for improvement. The ACI Care pathways for people with neurodegenerative and neuromuscular conditions diagnostic report draws together information about care issues for people affected by neurodegenerative and neuromuscular conditions in NSW. The diagnostic report reviewed current literature and practice as well as feedback and information from senior clinicians and peak bodies involved in neurodegenerative and neuromuscular diseases, and identified common issues and themes across conditions.

The findings of the diagnostic report show that people with neurodegenerative and neuromuscular conditions have complex care needs that require support across the continuum of care, spanning primary care, acute care, specialist services, and social and community care.

This Action areas for consideration by ACI Networks document aims to support ACI Networks to deliver and/ or enhance current and developing models of care to improve outcomes for people with neurodegenerative and neuromuscular conditions. It should be read in conjunction with the Summary report: diagnostic exercise.

Broad areas for action identified in this report include:

- building capacity
- improving access
- improving care
- working together.

Eight specific actions have been identified as priorities for ACI Networks. These actions are listed on Page 2 and are highlighted throughout the document in bold and blue.

Finally, this document provides the next steps, outlining the process towards achievement of the aims outlined in this paper.
The body of this document outlines a number of action areas for the consideration of the ACI Networks. These have been themed, and eight priorities for action identified.

1. Scope the development of an ND and NM Portal which could provide accredited training, clinical guidelines and peer networking and collaboration opportunities.

2. Explore opportunities for Chronic Disease Management and Integrated Care programs in NSW to support management of people with ND and NM conditions. Consider telephone triage and technological solutions for people with ND and NM conditions to improve coordination of care.

3. Building from the diagnostic report, develop a map of existing ND and NM services. Explore a model at a statewide level to determine where specialist services should be located, and how these should work collaboratively with distant, less specialised service providers (for example, through telehealth).

4. Explore options for inclusion of pathways that include triggers for referral to specialist respiratory failure services and palliative care in primary care patient management systems (for example, HealthPathways) and/or the ND and NM Portal.

5. Develop care plan guidelines (with possible inclusions of equipment, respite options, ventilation options, guardianship, communications, advance care plans and palliation) to support people with ND and NM conditions. These guidelines could be included in ND and NM condition modules within existing general practice management systems, for example HealthPathways. The guidelines could also contain information about Authorised Adult Palliative Care Plans through Ambulance NSW.

6. Explore opportunities for HealthDirect modules and/or services for people with ND and NM conditions.

7. The Palliative Care Network and the Respiratory Network to document and disseminate information regarding ventilation choices and palliative care.

8. The ACI Transition Network to identify potential obstacles to Key principles of care for young people transitioning to adult services and possible solutions.

These high priority action areas have been highlighted throughout the document in **bold and blue**. Recommendations that have not been identified as high priority areas either inform the high priority actions or can be considered for future work in the ND and NM space.
Section 3

An improvement snapshot

Neurodegenerative & Neuromuscular Conditions
improving care in NSW

NEURODEGENERATIVE (ND) CONDITIONS primarily affect the neurons in the brain, resulting in progressive degeneration of nerve cells, problems with movement or mental functioning.

ND conditions include Alzheimer’s disease\(^a\), Parkinson’s disease, Huntington’s disease, motor neuron disease and multiple sclerosis.

NEUROMUSCULAR (NM) CONDITIONS affect the muscles or their control.

There are more than 40 different types of NM conditions including muscular dystrophy, motor neuron disease and myopathies.

The impact and cost of ND&NM conditions on the individual, the community and the Australian health system is significant.

It is estimated that 35,400 people in NSW have one of the higher prevalence ND or NM conditions.

Key Action Areas

Building capacity
- statewide capacity & confidence
- empower people with ND&NM conditions
- recognition & support for carers

Improving access
- access to equipment
- access to palliative & supportive care services
- access to specialist services

Improving care
- addressing health inequities
- clinical pathways & guidelines
- access to respiratory support

Working together
- transitions for young people into adult services
- seamless coordination of care

\(^a\) Alzheimer’s Disease is ‘out of scope’ for this report because it is a key focus of the Framework for the Integration of Care for Older Persons with Complex Care Needs.

Prevalence of conditions in NSW

Infographic prepared by Healthy Partnerships 2015.
Neurodegenerative (ND) and neuromuscular (NM) conditions are a group of varied and rare conditions, which have a significant impact on individuals, their carers and communities. While each individual condition may be rare, their combined prevalence is significant.

- Neurodegenerative conditions primarily affect the neurons in the brain, resulting in progressive degeneration of nerve cells, problems with movement or cognitive functioning. ND conditions include Alzheimer’s disease, Huntington’s disease, Parkinson’s disease, motor neurone disease (MND) and multiple sclerosis (MS).
- Neuromuscular conditions affect the muscles or their control. There are more than 40 different types of NM conditions, including muscular dystrophy, MND and myopathies. NM diseases may be inherited or acquired. They may be present at birth or manifest in childhood or in adulthood. Life expectancy varies by disease and severity, from very short to normal length.
- Neurofibromatosis (NF) types 1 and 2 are tumour-susceptibility disorders that can result in progressive neurological impairments. NF can be inherited or present for the first time in a family. NF may be apparent from birth or, more commonly, its complications may become apparent in childhood or adulthood. Life expectancy varies by disease and by severity.

It is estimated that 35,400 people in NSW have one of the higher prevalence ND or NM conditions.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Prevalence</th>
<th>People affected in NSW – estimate (NSW pop. 7,300,000)</th>
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<tbody>
<tr>
<td>Parkinson’s disease</td>
<td>283:100,000¹</td>
<td>20,900</td>
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<tr>
<td></td>
<td>3400:100,000 over 55 years⁴</td>
<td></td>
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<tr>
<td>Multiple sclerosis⁵</td>
<td>100:100,000</td>
<td>8000</td>
</tr>
<tr>
<td>Neurofibromatosis 1⁶</td>
<td>33:100,000</td>
<td>3000</td>
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<tr>
<td>Neurofibromatosis 2</td>
<td>3:100,000</td>
<td></td>
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<tr>
<td>Muscular dystrophy ⁷</td>
<td>1:1000</td>
<td>7000</td>
</tr>
<tr>
<td>Motor neurone disease⁸</td>
<td>7:100,000</td>
<td>500</td>
</tr>
<tr>
<td>Huntington’s disease⁹</td>
<td>7:100,000</td>
<td>500</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td></td>
<td><strong>39,900 people</strong></td>
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Table 1a. Prevalence of ND and NM conditions in NSW

<table>
<thead>
<tr>
<th>Condition</th>
<th>Prevalence</th>
<th>People affected in NSW (estimate*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rare diseases⁹</td>
<td>6000:100,000</td>
<td>400,000</td>
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<tr>
<td>(*This data is based on European Commission data as Australian data is not available. It is unclear what % of rare diseases are ND and NM conditions.)</td>
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Table 1b. Estimate of prevalence of rare diseases in NSW

An estimated 400,000 people in NSW have a rare disease; many of these are ND and NM conditions (Table 1b). The impact and cost of ND and NM conditions on the individual, the community and the Australian health system is significant.

People with ND and NM conditions vary in their length of life and intensity of care needs. Prevalence only indicates a snapshot at any one time. Some diseases, such as MND, have a rapid progression with complex needs and high rates of death requiring intensive involvement by the healthcare team, especially allied health professionals. For example, while there may be 500 people living with MND at any one time there are at least 233 people newly diagnosed each year and over 213 deaths.
What does this report aim to achieve?

The ACI works with clinicians, consumers and managers to design and promote better healthcare in NSW. The ACI’s clinical networks work together across service and regional boundaries to implement improvements to healthcare through collaboration and shared learning and knowledge. This report aims to outline actions that will result in improved healthcare and quality of life for people with ND and NM conditions. The actions will be considered for implementation by the relevant clinical networks, in partnership with stakeholders. This report represents a significant body of work by the ND and NM Conditions Working Group, supported by the ACI.

To inform this *Action areas for consideration by ACI Networks* document, a diagnostic process was undertaken by the ND and NM Conditions Working Group and the findings outlined within the diagnostic report. The diagnostic report identified the case for change and highlighted service gaps and system failures for people with ND and NM conditions. The Action Areas workshop that followed clarified issues and transformed these into opportunities for improvement for ACI Networks. The ND and NM Conditions Working Group worked further on these to develop recommendations for the system for people with ND and NM conditions.

The Triple Aim describes three primary aims of healthcare: improving population health, improving patient experience and reducing per capita costs of healthcare. The Triple Aim can be used by implementation teams to ensure system interventions are cognisant of these three target outcomes of health system improvement, throughout design and improvement phases. The ND and NM Conditions Working Group have referenced the Triple Aim in their work to this point in recognition of the complexity in designing system improvements for people with ND and NM conditions.
Case study

In November 2012, my 15-year-old daughter ‘Emma’ (name changed for privacy reasons) was diagnosed with MS while on student exchange in France after suddenly becoming unable to move her left leg or left arm.

As part of her treatment in Lyon, she received in-hospital psychology, physiotherapy and occupational therapy services. If she was French, she would have been discharged on MS drug therapy with referrals to a range of community services. However, after being flown back to Australia, we struggled initially to have her diagnosis confirmed and for her treatment to start. In-hospital physiotherapy and occupational therapy halted abruptly as soon as she reached a basic benchmark. Upon discharge, there were no referrals made to services in the community.

After she was discharged from hospital, our local GP recommended a local psychology service. The psychologist we attended had no comprehension of Emma’s condition and was completely unsuited to her needs. I found the phone counselling provided by MS Australia very reassuring and effective. Our phone counsellor was also able to connect us to an exceptional psychologist who has helped Emma better understand and accept her condition and to look positively towards the future.

Emma’s paediatric neurologist is outstanding in his approach, care and accessibility. He has offered to keep Emma as a patient until her 19th birthday, and will assist with her transition to adult services. We have visited one of two possible adult MS clinics to look at options for Emma’s transition and met with an MS nurse at the clinic but found it perplexing as she gave us different advice to that given by Emma’s treating specialist and her GP.

Emma’s treating hospital was unable to connect her with any other young people with MS. As Emma said, if she had cancer she could go to cancer camp and meet other people her age going through the same experience as her. Emma found having MS a very lonely experience until we discovered MS Shift in the UK and she began to talk online with people her age in the UK and Canada. She still has no connections locally with people her own age with MS.

From the start I felt we were fighting for treatment and services and was astounded at the lack of services for young people, particularly those under 18.

Emma has amazed and delighted us with her resilience, maturity and determination. She has stuck with her prescribed drug therapies in spite of their debilitating side effects. Last year she finished high school with a fantastic score and has just completed her first year at university. Growing up with a chronic degenerative condition is an enormous challenge, but thanks to Emma’s mature approach and psychological counselling she has made a great start.

What would have helped
- Early consultation with an MS neurologist and open discussions on diagnosis and options.
- Psychological services while an inpatient and referrals to community based services after discharge.
- Automatic connection to MS Australia services.
- A readily accessible peer network for young people with MS.
- Assistance to ensure Emma’s return to school was effective and supported.
The broad recommendations to improve the experiences and outcomes for people with ND and NM conditions are outlined below. These recommendations are described in greater detail within this report.

<table>
<thead>
<tr>
<th>Building capacity</th>
<th>Improving access</th>
<th>Improving care</th>
<th>Working together</th>
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<td>Empower people with progressive neurological conditions by supporting and enabling their choices</td>
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<td>Provide early and ongoing access to respiratory support</td>
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The five co-sponsoring networks are the:

- Chronic Care Network
- Rehabilitation Network
- Palliative Care Network
- Transition Care Network
- Respiratory Network.
People with progressive conditions require timely access to specialist care and well-coordinated, multidisciplinary support services to maximise their quality of life and its longevity. This report focuses on key actions that will build this capacity and better identify and support the person with a ND and NM condition, and their family and carer(s).

Capacity-building refers to readiness for change, competency and capability development at an individual, organisational and partnership or sectoral level.

**DEVELOP STATEWIDE WORKFORCE CAPACITY AND CONFIDENCE**

The *ND and NM conditions diagnostic report* outlined areas requiring focused attention and intervention to improve workforce readiness, and the ability to support people with ND and NM conditions.

Developing capacity needs to occur across:

- **Individuals**: people with ND and NM conditions, carer(s), and healthcare and social service professionals
- **Organisations**: supporting the workforce to develop and maintain current skills and knowledge; ensuring local policies support appropriate practice; and reallocating resources to support delivery of appropriate services
- **Regions**: organisations working together at a local level to develop skills and knowledge, as well as negotiate partnerships to develop appropriate local responses to needs of people with ND and NM conditions.

**OPPORTUNITIES FOR IMPROVEMENT**

- Local areas should identify key stakeholders for people with ND and NM conditions, and determine how skills and knowledge can be obtained and shared. Particular audiences may be targeted, such as primary care or residential aged-care facilities (RACFs). Strategies may include:
  - regular web-based updates
  - local communities of practice
  - self-directed learning packages
  - webinars
  - travelling roadshows
  - telehealth.

- It may be beneficial for education providers to examine opportunities to become accredited providers of continuing professional development activities. For example, the Quality Improvement and Continuing Professional Development Program of the Royal Australian College of General Practitioners accredits providers of training activities. This may increase the perceived value of training to the recipient.

- Early links with organisations for people with ND and NM conditions should be facilitated by primary care providers. This may be achieved via information packs for general practice, training packages for primary care practitioners, or using other opportunities (such as telehealth) to communicate with primary care providers.

- The use of general practitioner (GP) specialists (for example, through primary health networks) may help to develop specialised expertise at a GP level.

- Efforts may be invested to identify models that are working effectively. This is of particular interest where specialist services may be more difficult to access, for example in RACFs or rural and regional areas.

- Finally, models which target workforce capacity need to be mindful of the ongoing role of specialist services; building capacity and facilitating access to specialist services are not mutually exclusive.
**Key actions**

- Building from the diagnostic report, develop an accessible map of existing services.
- Explore opportunities for HealthDirect modules and/or services for people with ND and NM conditions.
- Scope the development of an ND and NM Portal which could provide accredited training, clinical guidelines and peer networking and collaboration opportunities.
- Explore a model at a statewide level to determine where specialist services should be located, and how these should work collaboratively with distant, less specialised service providers (for example, through telehealth).
- Investigate opportunities to develop information technology to enhance capacity, similar to the ACI Trauma app, and by using e-health.
- Explore the possibility of developing specialist GP expertise through engagement with primary health networks.

**POTENTIAL BENEFITS**

Mapping services and collating contact details into a website, or other technology-based repository that is sustainable, accessible and available to all concerned, will allow health professionals, patients and patient groups to find services more efficiently.

A ND and NM Registry which links into a national registry and ultimately an international registry provides many opportunities to the health consumer and health professionals in relation to managing conditions, exploring future treatments, access to clinical trials and enabling NSW clinical trial sites that link both nationally and internationally.

Collecting data and information on people living with ND and NM conditions facilitates the sharing of new knowledge, which will help the development of improved coordinated care plans that meet the needs of people diagnosed with such conditions.

Registries of care and trial sites have significant utility for research into rare conditions such as NM diseases, as is demonstrated by the significant engagement by industry and other researchers with the TREAT-NMD Care and Trial Site Registry.\(^12\)
EMPOWER PEOPLE WITH PROGRESSIVE NEUROLOGICAL CONDITIONS BY SUPPORTING AND ENABLING THEIR CHOICES

People with progressive neurological conditions are often managing complex interactions with disparate care providers and trying to negotiate support across different services and sectors. It is essential that people with ND and NM conditions are supported to make choices about their own care.

In this context, empowering people refers to ensuring that people with ND and NM conditions:

- are appropriately equipped to manage their condition
- have the support needed to make choices and take more control and ownership of their health and care
- are working with respectful providers who support their active leadership in their own care.

By empowering people with ND and NM conditions, services need to reorient and partner to meet needs identified by patients. For example, people with ND and NM conditions may highlight the need to develop more home-based interventions, to resolve local transport issues, to examine options for housing, to develop alternative models for equipment supply or to advocate for carer support.

OPPORTUNITIES FOR IMPROVEMENT

- People with ND and NM conditions must be supported to be active decision-makers in their own care. Primary care plays a vital role in facilitating these decisions, whether the focus is on maximising function, treatment choices reflecting particular vulnerabilities or a shorter lifespan associated with the person’s condition. Services need to create partnerships to develop strategies and interventions to honour these decisions and meet the needs of patients.
- Some aspects of life, such as housing and accommodation, are limited in terms of consumer input and choice. There is a significant undersupply of respite and long-term accommodation for people with ND and NM conditions (many of whom are young). Consumers need choices that will give them real opportunities for managing their care and lives.
- It may be useful to highlight local successes in this area, to share successful strategies for patient-centred care and how local areas have translated patient choices into action.

Key actions

- **Explore opportunities for HealthDirect modules and/or services for people with ND and NM conditions.**
- Determine availability of, and investigate options for, online support packages that enable effective self-management by people with ND and NM conditions.
- Determine current availability of, and investigate options for, an online community that enables effective self-management and information sharing by people with ND and NM conditions.
- Investigate options for linking with and supporting primary care. One option for consideration is developing ND and NM condition modules within HealthPathways, or PrimaryCare Sidebar.
- Continue stakeholder engagement in directing design and development of services.
POTENTIAL BENEFITS

Online support packages
Recent research suggests that around 60% of patients source internet-based information about medical conditions and treatment. Online support packages enabling effective self-management by people living with ND and NM conditions allow people diagnosed with these diseases the ability to inform and give consent to their own disease management.

Creating ND and NM condition modules that raise awareness and increase knowledge in primary care enables primary carers to develop coordinated, multidisciplinary care plans that are both relevant and appropriate to people diagnosed with ND and NM conditions.

Online communities
Availability of and accessibility to online communities improves two-way communication between people living with such conditions. Sharing information on experiences of living with such conditions can increase knowledge of the conditions. Existing online communities, such as PatientsLikeMe (USA), let patients communicate with one another and answer specific health-related questions, proffer personally acquired disease-management knowledge to those most likely to benefit from it, and foster and solidify relationships based on shared concerns.

Stakeholder engagement
Seeking stakeholder engagement can lead to new and innovative models of care. A systematic interview and survey of young adults with NF1 identified skin complications of neurofibromatosis as a major concern affecting quality of life. A quality improvement project was developed as part of the Clinical Excellence Commission’s Clinical Leadership Program that, with further stakeholder involvement of patients, carers and families, and multidisciplinary clinicians, designed a strategy to improve the care of the skin complications of NF, and assess the impact of this on quality of life. With temporary funding from the Children’s Tumour Foundation of Australia (CTF), an NF skin clinic has been initiated at the Royal North Shore Hospital (RNSH) with dermatology, genetics and CTF involvement.
**IMPROVE RECOGNITION AND ADVOCACY/SUPPORT/ENABLEMENT FOR CARERS**

ND and NM conditions have a profound impact on the quality of a person's life, and that of their families. Carers frequently adopt the role of care coordinator: communicating across service and sector boundaries; relaying information from one health professional to another; managing advice; planning next steps; and managing costs and billing issues. Carers may also be the primary advocate for a person with ND and NM conditions.

**OPPORTUNITIES FOR IMPROVEMENT**

- The expertise of carers should be valued. The critical role of carers in setting goals and planning care should be respected and supported; carers' voices should be heard and represented.
- The challenges faced by carers should be recognised so they are supported with information, services (for example, respite), tools and resources (for example, carer support).
- Recognition should be given that carers often engage in clinical tasks; carers should be provided with education and training as needed. Carers should be supported to train paid care providers as appropriate.
- Relevant partnerships that will improve carers’ access to Carers Australia and other carer resources (for example, respite) should be identified.

**POTENTIAL BENEFITS**

Carers play a crucial role for people diagnosed with complex chronic ND and NM conditions. By supporting the carers, patient health outcomes can be better managed and improved.

**Role of carers**

There are many advantages for the individual receiving assistance from an informal carer. These include the potential for avoiding or delaying entry into formal residential care or hospital settings, greater inclusion in the community, and better quality of life – including physical and mental health – that comes from remaining in the community.15

**Supporting carers**

Carers may become ill themselves unless adequate support is given to them throughout the course of the disease. Research has shown that providing support for carers, through maintenance of social support, activities and a positive outlook, may lessen the chance of ill health arising from long hours spent caring. It is also found that having a named care coordinator may assist with access to resources, and provide practical and emotional support during and after the caring role.16

By collaborating with Carers Australia (NSW), duplication of effort can be minimised.

**Key actions**

- Scope the development of an ND and NM Portal which could provide accredited training, clinical guidelines and peer networking and collaboration opportunities (with a link to the Carers NSW website).
- Consider opportunities to link with and provide content to HealthDirect.
People with ND and NM conditions have complex needs that may change rapidly throughout lifespans. As needs change, there must be opportunities to access relevant and appropriate services, in a timely manner. Delays in access to appropriate services may result in negative outcomes, including compromised care, limited access to the community and potentially avoidable hospital admissions. The ND and NM diagnostic report outlined some access issues that impact significantly on the lives of people with ND and NM conditions.

**ENHANCE ACCESS TO SPECIALIST SERVICES**

Access to specialist clinics and services can prove challenging for some people with ND and NM conditions. Presenting with multiple and complex needs, people with ND and NM conditions may have difficulty navigating a complicated system of care, where multiple specialist services may be needed. Primary care providers may also have difficulty directing their patients to appropriate and accessible services.

Delays in accessing initial or subsequent specialty consultations (for example, outpatient waiting lists) can lead to delays in correct diagnoses and management plans. Many aspects of multidisciplinary care and management are not available to patients until a specialist’s assessment has been completed. Timely access to specialist outpatient services is needed to ensure appropriate interventions and management can be initiated to reduce preventable complications and improve patient outcomes.

Some specialist services may not be available in all local health districts (LHDs). This may be appropriate in some cases of rare disorders, where specialty expertise may need to be concentrated in one service to ensure sufficient patient exposure. This is the case for instance in NF2 surgical expertise, where outcomes are better the more expertise the surgeon has with this particular patient group. Limiting access to area-specific regions can have a negative impact on patient outcomes if they are refused access to this specialty expertise.

Additionally, some priority groups have much lower rates of access to specialist services, including Aboriginal people, people from culturally and linguistically diverse backgrounds, people living with unrecognised rare diseases and people experiencing social disadvantage.

Access issues are of particular concern for rural and remote communities, where health services are largely driven by primary care, have less infrastructure and fewer local specialist services. Some patients travel great distances to see specialists and may need to see a number of specialists all based from different clinics, hours from home. The challenges of rural and remote service access, however, can drive the development of innovative ideas and practices, including extended scope practitioners, use of new technologies such as telehealth, and interdisciplinary care models.

A multidisciplinary coordinated care approach is ideal for multidimensional diseases that involve a range of symptoms and require different levels of service across the course of their disease, which may also be episodic (as in the case of MS). People with ND and NM conditions may require varying levels of service across the course of their disease from community to admitted and ambulatory services.

Multidisciplinary rehabilitation care can support the person with an ND or NM condition to maintain their function and independence for as long as possible, allowing them to participate fully in their family and community. As the speciality with unique skills in bridging the gap between hospital and community, multidisciplinary rehabilitation care should be considered for early referral. The rehabilitation model of care also promotes the use of hub and spoke models to support smaller sites.
OPPORTUNITIES FOR IMPROVEMENT

- Continuity of care should be provided through clear and ongoing communication and care coordination efforts across primary care and specialist services.

- Access to specialist clinics should be facilitated by identifying clinics, clearly establishing the roles of each clinic, and developing clear referral pathways and processes with identified points of contact.

- Well-established clinics can share their experience to support replication.

- An established central contact point (for example, phone line, email) for clinics could link to:
  - clinical nurse consultants\(^{18}\)
  - advice and other services
  - GP software
  - a directory of services and accredited clinicians.

- A hub and spoke model for statewide access to specialist services and clinics is required, recognising that some conditions may need several hubs and others may only need one.

- Telehealth can reduce the need for travel.

- Telehealth can also be used to provide multidisciplinary assessments by linking clinicians in real time to the patient and to each other.

- Equity of access to specialists (including allied health) could be promoted by:
  - mentoring clinicians
  - outreach models
  - telehealth models for removing LHD boundary limitations to access where appropriate.

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**Key actions**

- Explore a model at a statewide level to determine where specialist services should be located, and how these should work collaboratively with distant, less specialised service providers.

- Explore opportunities for Chronic Disease Management and Integrated Care programs in NSW to support management of people with ND and NM conditions. Consider telephone triage and technological solutions for people with ND and NM conditions to improve coordination of care.

- Examine opportunities to work with HealthDirect to improve access to specialist clinics, including:
  - linking to advice
  - linking to a directory of services and accredited clinicians
  - using a video call service.

- Identify well-established clinics and share their experience via an ND and NM Portal and ACI Networks to support replication. Identify options for improving equity of access through mentoring, outreach models and telehealth models.

- Explore ways to improve access to multidisciplinary team assessments.
POTENTIAL BENEFITS

Multidisciplinary care

An evidence-based review of the care of patients with amyotrophic lateral sclerosis (ALS) showed that multidisciplinary clinics specialising in ALS care can be effective in several ways, including: increased use of adaptive equipment; increased use of medication (riluzole), percutaneous endoscopic gastrostomy (feeding tube), and non-invasive ventilation (NIV); improved quality of life; and lengthened survival.19

The review recommended that specialised multidisciplinary clinic referrals should be considered for patients with ALS to optimise healthcare delivery and prolong survival, and may be considered to enhance quality of life.20
PROVIDE TIMELY AND APPROPRIATE ACCESS TO EQUIPMENT

Please note: Due to the rollout of the National Disability Insurance Scheme (NDIS) across NSW from 1 July 2016, this key action area is likely to undergo a great deal of change. Exactly how the NDIS will impact patients’ ability to access equipment in a timely and appropriate manner is unknown at this stage.

Access to prescribed equipment for people with ND and NM conditions can be costly and slow, preventing people from obtaining the equipment they need. Lengthy waiting periods for access to services (for example, allied health) delay access to equipment and modifications.

Strategies to resolve issues with access to equipment must recognise the complexities of equipment access in regional, rural and remote areas.

The Motor Neurone Disease Association of NSW service, FlexEquip, provides short- to medium-term (three to six months) equipment loans to people with rapidly progressive ND and NM conditions (MND, MS and muscular dystrophy). The loan pool is limited to specific items (primarily for mobility and communication) that are not modified. They are provided, on average, within one or two weeks of application.

OPPORTUNITIES FOR IMPROVEMENT

• There is a need to identify and explore how effective equipment models are working to better meet the needs of people with ND and NM conditions. Options need to be explored to facilitate timely access to equipment. This may include equipment hire (as opposed to purchase), or establishing a loan pool for recycling and reallocating equipment that can be used by more than one patient (consecutively). A more flexible approach to equipment prescription that allows proactive anticipation of the future needs of people with ND and NM conditions may also assist with timely access to equipment.

• Primary care coordinators (GPs or other) should be kept in touch with changing needs so they can facilitate timely referral for equipment prescription.

• Problematic local models of equipment provision should be process mapped to identify areas impacting negatively on the service delivery. These should be targeted for improvement.

Key actions

• Explore opportunities to improve equipment access, with a particular focus on planning ahead and timely access.

• Engage with EnableNSW, primary health networks and other interested parties to develop a guide to planning for and accessing equipment. This guide may be linked to HealthPathways, Map of Medicine or other general practice systems.

• Explore greater opportunities for FlexEquip to complement EnableNSW by providing short- to medium-term loans prior to EnableNSW provision.

• Broaden FlexEquip’s services to include people with rapidly progressive or episodic ND and NM conditions such as Parkinson’s Plus.
POTENTIAL BENEFITS

Timely access to equipment

People diagnosed with ND and NM conditions progress at different rates. The need to access equipment efficiently and without delay is beneficial for the patient, the carer and health outcomes for all concerned.

Facilitated access to equipment could allow people diagnosed with ND and NM conditions an improvement to quality of life, mental health and overall health outcomes.

In a Victorian study on the provision of equipment to disabled clients, 26 responses were received from staff working in 12 different agencies. When asked about the impacts on clients and carers of equipment delays and unmet need, 18 respondents indicated that clients experienced stress or depression; 16 indicated there were consequences for clients’ physical health; 12 indicated that clients suffered exclusion; and 12 indicated that delays caused isolation for clients. All of these impacts reduce quality of life and increase dependency.21
IMPROVE ACCESS TO PALLIATIVE AND SUPPORTIVE CARE SERVICES

Every person in NSW is entitled to have access to high quality care that addresses their physical, psychosocial and spiritual needs as they approach and reach the end of their life. The *Palliative and end of life care: blueprint for improvement* (2014) emphasises the need for an integrated approach to care that fosters relationships between specialist palliative care providers and care providers across all settings of care. Some individuals with ND and NM conditions are likely to have shorter lives and a proportion may experience complex symptoms or problems that would benefit from specialist palliative care advice as their health deteriorates. In some instances, shared care of the person by their primary professional and palliative specialist may be important.

As discussed in the section on building capacity, early conversations between the treating physician and patient about the possibility of a shorter lifespan or particular vulnerabilities associated with the person’s ND and NM condition provide a basis for further discussions when the doctor assesses that their patient may be entering the last year of their life. These later conversations provide an opportunity for treatment and care choices to be thought through with the person and their family and documented as appropriate.

OPPORTUNITIES FOR IMPROVEMENT

- There is a need to inform and educate people about the nature of palliative care, which is more than just end-of-life. Care providers across settings are able to participate in care for people approaching the end of their life, with support, education and appropriate resourcing.\(^{22}\)

- Providers need to work together with the person with an ND or NM condition and their family to determine the most appropriate care to meet their needs. Services need to be well-coordinated and flexible in adapting to changing needs over time. There is a need to identify when specialist palliative care services are required and make appropriate and timely referrals.

- Best practice guidelines for health professionals serving people with ND and NM conditions likely to reduce their lifespan should include provision for early conversations on relevant treatment decisions.

Key actions

- Develop care plan guidelines (with possible inclusions of equipment, respite options, ventilation options, guardianship, communications, advance care plans and palliation) to support people with ND and NM conditions. These guidelines could be included in ND and NM condition modules within existing general practice management systems, for example HealthPathways. The guidelines could also contain information about Authorised Adult Palliative Care Plans through Ambulance NSW.

- Explore options for inclusion of pathways that include triggers for referral to specialist respiratory failure services and palliative care in primary care patient management systems (for example, HealthPathways) and/or the ND and NM Portal.

- Document and disseminate information regarding ventilation choices and palliative care.
POTENTIAL BENEFITS

Authorised Adult Palliative Care Plans

NSW Ambulance reports that 50% of patients attended by NSW Ambulance who have an Authorised Palliative Care and End-of-Life Care Plan in place are not transported to the emergency department (ED). The overall impact for the hospitals is fewer patients occupying a bed in the ED or being admitted beyond the ED. There are cost savings for the ED based on the average cost of an ED encounter. For the patient, it means they have a choice to remain at home for their care and NSW Ambulance is able to contribute to the wishes of the patient. In addition, the benefit to NSW Ambulance is fewer patient presentations to the ED, as well as the benefit of respecting the wishes of the patient.23

Palliative care pathways

In a joint position statement, Palliative Care Australia and the Neurological Alliance Australia called for a national framework for people living with neurological conditions that outlines a pathway for palliative care service provision. The statement also recommends early, comprehensive and accessible information on palliative care for people with neurological conditions, their families and carers.24
ADDRESS HEALTH INEQUITIES

Some population groups in Australia experience marked health inequalities compared with the general population. These populations include: Aboriginal and Torres Strait Islander people; people living in rural and remote areas; people with disability; particular migrant groups; older people and people living with rare diseases.

The NSW community is diverse with over 7.2 million people living in the state. Of these, 2.5% identify as Aboriginal and/or Torres Strait Islander persons. Over 30% of the population was born overseas and nearly one in four people speak a language other than English at home.

Some groups of people in NSW continue to experience significantly worse outcomes than their peers. Aboriginal and Torres Strait Islander peoples continue to experience significantly shorter life expectancies and greater burden of chronic diseases, chronic disease-related complications and mortality. The NSW Government is committed to closing the health and life expectancy gap between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians within a generation.

People from culturally and linguistically diverse backgrounds may experience significant healthcare access issues and be unable to obtain culturally appropriate services. Recent arrivals to Australia may have limited support networks, which reduces access to information and care. People who are socially disadvantaged also face worse outcomes, experiencing greater complexities of chronic conditions and comorbidities, and significant interactions between social conditions and disease management.

Patients presenting to specialist hubs may travel across LHD boundaries to access care. These patients are not always able to access appropriate local support services, for example, Aboriginal Liaison Officers, at the treating institution.

There is an opportunity to actively target inequities in the health of people in NSW.

Services for people with ND and NM conditions must respect cultural and religious beliefs about illness, medical treatment, and death and dying.

OPPORTUNITIES FOR IMPROVEMENT

- A partnership approach is central to the design of culturally sensitive solutions for Aboriginal people with ND and NM conditions. Linking with relevant bodies, such as the Aboriginal Health and Medical Research Council (AHMRC), Aboriginal Community Controlled Health Services (ACCHS) and primary health networks will enable appropriate approaches to be developed. For example, approaches should:
  - undertake systematic process to embed Aboriginal Health principles in a model of care
  - link to Aboriginal Health Plan (and Aboriginal Housing Information Service) and related plans/frameworks
  - develop resources and tools designed by and for Aboriginal peoples and communities
  - provide culturally appropriate services, starting with cultural awareness training for all people involved in Aboriginal healthcare
  - link in Aboriginal communities to provide education relating to local services
  - meet and include local Aboriginal elders of communities in service planning, design and implementation
  - work with the Aboriginal health system such as Aboriginal health workers and Aboriginal Liaison Officers
  - encourage identification for Aboriginal and Torres Strait Islander peoples as per the NSW Health commitment.
• Identification of successful models nationally may assist the development of locally appropriate methodology and models of care.

• Local support, for example, Aboriginal Liaison Officer services, should be available to patients at their treating hospital regardless of the patient’s address.

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**Key actions**

- Work together with LHD Aboriginal health services, ACCHS and AHMRC to identify successful models for Aboriginal people with ND and NM conditions, their families and communities. Share experiences via an ND and NM Portal, ACI Networks and other relevant networks to support replication.

- Support services to develop or enhance culturally appropriate models of care for people with ND and NM conditions.

- Support access to local Aboriginal and cultural and linguistically diverse services at treating hospitals, regardless of the patient’s address.

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**POTENTIAL BENEFITS**

**Culturally appropriate models of care**

Developing culturally appropriate models of care may enhance the consumer’s experience and willingness to engage earlier with health services.  

A 2011 study found significant links between the patients’ perceptions of the cultural sensitivity of the healthcare provider and the patients’ adherence to treatment regimens recommended by the provider, health behaviours and health outcomes.
DEVELOP AND IMPLEMENT CLINICAL PATHWAYS AND GUIDELINES

People with ND and NM conditions navigate a complex service system, sometimes accessing several specialist services, equipment providers and primary care providers as well as managing daily demands such as medication, equipment and billing. Additionally, people with ND and NM conditions are often diagnosed relatively late in their disease progression, requiring greater input in initial stages.

Availability and organisation of services vary across the state, and geography has a significant impact on access to services and services provided.

Specialist knowledge about ND and NM conditions is often not available to primary care providers or people with ND and NM conditions. There is an opportunity to improve care for people with ND and NM conditions by developing and implementing clinical pathways and guidelines with a much more coordinated approach. These may be designed for use by specialist clinics, people with ND and NM conditions, or by primary care providers, with the aim of moving towards care that is consistent with current evidence and appropriate to the individual.

OPPORTUNITIES FOR IMPROVEMENT

- Patients and GPs would benefit from access to clinical guidelines and established care pathways. People with ND and NM conditions need equitable access to resources that come from a self-management perspective and support patient-centred care.
- Mapping existing services and clarifying referral processes and pathways will aid in early diagnosis and treatment.
- Development of clinical pathways, access to appropriate and effective care, diagnostic testing and treatment is essential.

Key actions

- Scope the development of an ND and NM Portal which could provide accredited training, clinical guidelines and peer networking and collaboration opportunities.
- Explore a model at a statewide level to determine where specialist services should be located, and how these should work collaboratively with distant, less specialised service providers (for example, through telehealth).
- Investigate options for linking with and supporting primary care. One option for consideration is development of ND and NM condition modules within HealthPathways, or PrimaryCare Sidebar.
- Examine opportunities to work with HealthDirect to improve access to specialist clinics, to:
  - link to advice
  - link to a directory of services and accredited clinicians.
**POTENTIAL BENEFITS**

Clinical guidelines

TREAT-NMD (a European-based network for the treatment of neuromuscular conditions) notes that the relative rarity of individual neuromuscular diseases means that until recently there has not been any consensus among doctors about how best to care for patients. Consequently, care standards differ not only from country to country but also even within individual countries. Not only does this impact on quality of life, it also makes clinical trials of promising new treatments much harder to carry out, because it is impossible to compare results from different centres if patients are cared for in different ways. By producing consensus guidelines agreed by doctors and patient groups, it is possible to improve this situation and make best practice care more widespread across the world.28
PROVIDE EARLY AND ONGOING ACCESS TO RESPIRATORY SUPPORT

Respiratory complications are common for people with ND and NM conditions and are the most common cause of mortality and morbidity. Timely referral for assessment, preventive care and intervention for respiratory complications are effective and cost-effective, and improve mortality and morbidity and quality of life.

Non-invasive ventilation is an effective means of resolving respiratory failure and improving outcomes for patients. NIV was traditionally provided in a critical care setting; however, some patients can be managed effectively in alternative settings with appropriate resourcing, expertise and staffing. The ACI’s domiciliary NIV model of care describes a hub and spoke model for delivery of NIV. These services would be supported by a standardised referral system and shared information management systems.

Timely access to safe effective equipment, and particularly specialised equipment, is key to maintaining quality of life and maximising lifespan. Any significant lag time in availability militates against the best possible health outcome for the patient and places unnecessary stress on carers and family.

OPPORTUNITIES FOR IMPROVEMENT

- Education of people with ND and NM conditions, carers and healthcare providers will increase awareness of early respiratory signs and symptoms, and improve identification of triggers for referral. Education modules, information and tools for general practice would be beneficial.
- Specific clinical pathways that define timely access to respiratory and sleep clinical services for assessments and management are needed for rapidly progressing neuromuscular diseases.
- ACI’s Domiciliary non-invasive ventilation in adult patients: a consensus statement should be put into operation. This consensus statement outlined key aspects of clinical care for people requiring NIV, providing current best practice guidelines for the assessment, management and ongoing care of adults requiring NIV at home.

Key actions

- Scope the development of an ND and NM Portal which could provide accredited training, clinical guidelines and peer networking and collaboration opportunities.
- Identify obstacles to implementation of recommendations within ACI’s Domiciliary NIV consensus statement.
- Investigate options for linking with and supporting primary care providers. One option for consideration is development of ND and NM condition modules within HealthPathways, or PrimaryCare Sidebar.

POTENTIAL BENEFITS

Non-invasive ventilation

Studies have shown that respiratory muscle function significantly predicts survival and quality of life in patients with MND. The management of respiratory symptoms and maintenance of lung compliance are particularly important. NIV has been proven to prolong life and maintain quality of life in patients with MND.
People with ND and NM conditions have multi-system medical problems. Services for people with ND and NM conditions cross service, organisational and sectoral boundaries, and may include many specialists, in addition to primary care, allied health and social support services. For this reason, particular efforts must be invested in working together to ensure equitable access to appropriate and well-coordinated care.

**PROVIDE SEAMLESS COORDINATION OF CARE**

Care coordination is a comprehensive approach to deliver more effective health management for people with long-term or complex conditions. Central to coordinated care is the person with an ND or NM condition. Seamless coordination of care depends on:

- active participation and decision-making in the planning and processes of care by the person with an ND or NM condition
- effective communication processes and tools to support shared information and care planning
- a collaborative, teamwork approach across service providers, together with the person with an ND or NM condition and their carer(s).

The Care Coordination Model is often associated with managing chronic conditions and coordinating views from the perspective of a patient-centred medical home. The model focuses on:

- assuming accountability
- providing patient support
- building relationships and agreements among providers
- developing connectivity via electronic or other information pathways that encourage timely and effective information flow between providers.

**OPPORTUNITIES FOR IMPROVEMENT**

- Strategies to improve coordination of care for people with ND and NM conditions, including responsiveness to fluctuations in care needs, should be identified.
- A key point/person for initial contact for troubleshooting and crisis prevention should be identified. Consider case management provided by an allied health professional to improve efficiency of healthcare use. Clinical nurse consultants for specialty case management improve efficiency of use of complex services for people with NF1.35
- Collaborative approaches across hubs and spokes will facilitate communication and information sharing and help to provide seamless accessible care.
POTENTIAL BENEFITS

Care coordinators

A review: carers, MND and service provision found that having a named care coordinator plays an important role in supporting carers by providing access to resources, and providing practical and emotional support during and after the caring role.\(^{36}\)

Coordination of clinical care is a crucial component of the management of Duchenne muscular dystrophy (DMD). This care is best provided in a multidisciplinary setting in which the individual and family can access expertise for the required multisystem management of DMD in a collaborative effort. A coordinated clinical care role can be provided by a wide range of healthcare professionals depending on local services, including (but not limited to) neurologists or paediatric neurologists, rehabilitation specialists, neurogeneticists, paediatricians and primary care physicians. It is crucial that the person responsible for the coordination of clinical care is aware of the available assessments, tools and interventions to proactively manage all potential issues involving DMD.\(^{37}\)

Key actions

- Explore opportunities for Chronic Disease Management and Integrated Care programs in NSW to support management of people with ND and NM conditions. Consider telephone triage and technological solutions for people with ND and NM conditions to improve coordination of care.
- Explore a model at a statewide level to determine where specialist services should be located, and how these should work collaboratively with distant, less specialised service providers (for example, through telehealth).
- Identify primary healthcare providers for each speciality within LHDs to help integrate care of complex patients.
PLAN AND COORDINATE TRANSITIONS FOR YOUNG PEOPLE INTO ADULT SERVICES

Transitions from paediatric to adult services for young people are fraught with difficulties. Young people are often shifting from a highly specialised and well-coordinated system of care into adult care that is often very different to the paediatric setting. Adult care is often ill-equipped to work with young people, being less coordinated and often involving a range of specialist services located at different sites. Additionally, at time of transition, young people are leaving services that have worked with them over time and developed strong positive working relationships. If transition is not managed effectively, then young people can experience significant health impacts.

The transition process will be different for each young person. The health system should respond to developmental needs of young people and young adults, and recognise the varying development stages of adolescents. In planning transitions, providers need to differentiate between those patients who can gain independence (with parental support) and those who cannot gain independence.

OPPORTUNITIES FOR IMPROVEMENT

- The ACI Transition Network’s Key principles of care for young people transitioning to adult services should be applied to people with ND and NM conditions. This includes:
  - Designating a transition coordinator/case manager to act as a single point of contact for clinical advice and information
  - Implementing a systematic transition plan and identifying a centralised point for overseeing care and for emergency care. The plan should include transitions across specialists as well as across clinics
  - Empowering, encouraging and enabling young people to manage themselves and get support through health coaching
  - Underpinning transition processes with formal guidelines and policies
  - Ensuring communication between paediatric and adult services. Sharing electronic records across LHDs will facilitate this, for example, allowing adult services to access a child’s hospital PowerChart. Centralised clinics must work closely with and communicate with local hospitals and the central point of contact.

- The different equipment needs of children and adults should be recognised early in the process of transition.

- Care should be tailored to the needs of each person because of the variable needs of people with ND and NM Conditions. Greater coordination of care between the Chronic Disease Management and Integrated Care programs in NSW would support management of people with ND and NM conditions.

- Telehealth has the potential to enhance the transition between paediatric and adult services.

- The point of transition and a clear pathway should be clearly identified and seamless coordination of services should be provided through a care coordinator model.

- The co-location of paediatric and adult specialists within clinical services can avoid the need for transitioning where possible. For example, the neurofibromatosis clinic at RNSH includes paediatric and adult specialists within its team, avoiding the need for transition of care. A similar model exists for NF care at St Guys Hospital in the UK.
POTENTIAL BENEFITS

Transition plans

In a systematic review of transition models for young people with long-term conditions, the overarching theme from the findings was the requirement for a formal transition process for young people with long-term conditions. The review found that a transition program should be embedded in service delivery with a written protocol/roadmap detailing the steps involved.38

Key actions

* The ACI Transition Network to identify potential obstacles to Key principles of care for young people transitioning to adult services and possible solutions.

* Identify well-established transition models and expand to document a model that could be replicated. For example, a modern multidisciplinary transition clinic or an extended transition clinic with a mixed care adolescent clinical nurse consultant. Consider sharing information via an ND and NM Portal.
Section 12
Next steps

This report has identified a number of action areas to target in order to improve care for people with ND and NM conditions. The report suggests some areas for further investigation and some areas for action, ranging from immediately applicable improvements to the service system to those which will take more collaborative and concerted efforts over time. Importantly, this process has reinforced the key roles of people with ND and NM conditions and their carers in planning and decision-making, and the role of health and social systems to empower and support this role.

Next steps will involve consultation with ACI Networks on the prioritised actions in the areas of:

- scoping an ND and NM online portal
- statewide ND and NM conditions service mapping
- documenting lessons learned from the Chronic Disease Management Program
- end of life care plan guidelines
- online support for ND and NM patients, families and carers
- palliative care and ventilation information
- palliative care content for HealthPathways
- key principles of care for transition to improve the experiences and outcomes of people with ND and NM conditions.
## Appendix 1

### Commonly used services for ND and NM diseases

<table>
<thead>
<tr>
<th>ND and NM disease</th>
<th>Services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Neurofibromatosis 1</strong></td>
<td>Dermatology, Ear, nose, throat (ENT) surgery, General surgery, Genetic counselling, Genetics, IVF services, Neurology, Neurosurgery, Oncology, Ophthalmology, Orthopaedic surgery, Pain clinic, Plastic surgery, Psychology</td>
</tr>
<tr>
<td><strong>Neurofibromatosis 2</strong></td>
<td>Audiology, ENT surgery, Genetic counselling, Genetics, Neurology, Neurosurgery, Ophthalmology, Plastic surgery, Psychology</td>
</tr>
<tr>
<td><strong>Parkinson’s disease</strong></td>
<td>Dietetics, Exercise physiology, Neurology, Neurosurgery, Occupational therapy, Pharmacy, Physiotherapy, Psychology, Social work, Specialist nursing, Speech therapy</td>
</tr>
<tr>
<td><strong>Huntington’s disease</strong></td>
<td>Clinical genetics, Dietetics, Genetic counselling, General practice, Neurology, Neuropsychology, Nursing, Occupational therapy, Physiotherapy, Psychiatry, Psychology, Social work, Speech therapy</td>
</tr>
<tr>
<td><strong>Muscular dystrophy</strong></td>
<td>Cardiology, Clinical genetics, Dietetics, Gastroenterology, Genetic counselling, General practice, Neurology, Neuropsychology, Occupational therapy, Orthopedics, Physiotherapy, Rehabilitation, Respiratory, Speech pathology</td>
</tr>
<tr>
<td><strong>Multiple sclerosis</strong></td>
<td>Clinical psychology, Complementary therapy (e.g. yoga, acupuncture, massage), Continence advice, Counselling, Exercise physiology, General practice, MS nursing, Neurology, Neuropsychology, Occupational therapy, Physiotherapy, Rehabilitation, Respiratory, Social work, Urology</td>
</tr>
<tr>
<td><strong>Motor neurone disease</strong></td>
<td>Dietetics, Gastroenterology, Genetic counselling, General practice, Home care nursing, Neurology, Occupational therapy, Orthotics, Palliative care, Physiotherapy, Psychology, Rehabilitation, Respiratory, Social work, Specialist nursing, Speech therapy</td>
</tr>
</tbody>
</table>

*Please note: While this document is relevant for all ND and NM conditions, this table does not contain an exhaustive list of ND and NM conditions. Also note that this is not an exhaustive list of services used in the care of people with these conditions. In addition to the above services, people may require services such as residential care, personal carers, domestic assistance, community case management and access to Aged Care Assessment Teams.*
## Building capacity

### Develop statewide workforce capacity and confidence

- Building from the diagnostic report, develop an accessible map of existing services.
- Explore opportunities for HealthDirect modules and/or services for people with ND and NM conditions.
- Scope the development of an ND and NM Portal which could provide accredited training, clinical guidelines and peer networking and collaboration opportunities.
- Explore a model at a statewide level to determine where specialist services should be located, and how these should work collaboratively with distant, less specialised service providers (for example, through telehealth).
- Investigate opportunities to develop information technology to enhance capacity, similar to the ACI Trauma app, and by using e-health.
- Explore the possibility of developing specialist GP expertise through engagement with Primary Health Networks.

### Empower people with progressive neurological conditions by supporting and enabling their choices

- Explore opportunities for HealthDirect modules and/or services for people with ND and NM conditions.
- Determine availability of, and investigate options for, online support packages that enable effective self-management by people with ND and NM conditions.
- Determine current availability of, and investigate options for, an online community that enables effective self-management and information sharing by people with ND and NM conditions.
- Investigate options for linking with and supporting primary care. One option for consideration is developing ND and NM condition modules within HealthPathways, or PrimaryCare Sidebar.
- Continue stakeholder engagement in directing design and development of services.

### Improve recognition and advocacy/support/enablement for carers

- Scope the development of an ND and NM Portal which could provide accredited training, clinical guidelines and peer networking and collaboration opportunities (with a link to the Carers NSW website).
- Consider opportunities to link with and provide content to HealthDirect.
### Improving access

**Enhance access to specialist services**

- Explore a model at a statewide level to determine where specialist services should be located, and how these should work collaboratively with distant, less specialised service providers.
- Explore opportunities for Chronic Disease Management and Integrated Care programs in NSW to support management of people with ND and NM conditions. Consider telephone triage and technological solutions for people with ND and NM conditions to improve coordination of care.
- Examine opportunities to work with HealthDirect to improve access to specialist clinics, including:
  - linking to advice
  - linking to a directory of services and accredited clinicians
  - using a video call service.
- Identify well-established clinics and share their experience via an ND and NM Portal and ACI Networks to support replication. Identify options for improving equity of access through mentoring, outreach models and telehealth models.
- Explore ways to improve access to multidisciplinary team assessments.

**Provide timely and appropriate access to equipment**

- Explore opportunities to improve equipment access, with a particular focus on planning ahead and timely access.
- Engage with EnableNSW, primary health networks and other interested parties to develop a guide to planning for and accessing equipment. This guide may be linked to HealthPathways, Map of Medicine or other general practice systems.
- Explore greater opportunities for FlexEquip to complement EnableNSW by providing short- to medium-term loans prior to EnableNSW provision.
- Increase and broaden FlexEquip’s services to include people with rapidly progressive or episodic ND and NM conditions such as Parkinson’s Plus.

**Improve access to palliative and supportive care services**

- Develop care plan guidelines (with possible inclusions of equipment, respite options, ventilation options, guardianship, communications, advance care plans and palliation) to support people with ND and NM conditions. These guidelines could be included in ND and NM condition modules within existing general practice management systems, for example HealthPathways. The guidelines could also contain information about Authorised Adult Palliative Care Plans through Ambulance NSW.
- Explore options for inclusion of pathways that include triggers for referral to specialist respiratory failure services and palliative care in primary care patient management systems (for example, HealthPathways) and/or the ND and NM Portal.
- Document and disseminate information regarding ventilation choices and palliative care.
## Improving care

### Address health inequities

- Work together with LHD Aboriginal health services, ACCHS and AHMRC to identify successful models for Aboriginal people with ND and NM conditions, their families and communities. Share experiences via an ND and NM Portal, ACI Networks and other relevant networks to support replication.
- Support services to develop or enhance culturally appropriate models of care for people with ND and NM conditions.
- Support access to local Aboriginal and cultural and linguistically diverse services at treating hospitals regardless of the patient’s address.

### Develop and implement clinical guidelines and pathways

- **Scope the development of an ND and NM Portal which could provide accredited training, clinical guidelines and peer networking and collaboration opportunities.**
- **Explore a model at a statewide level to determine where specialist services should be located, and how these should work collaboratively with distant, less specialised service providers (for example, through telehealth).**
- Investigate options for linking with and supporting primary care. One option for consideration is development of ND and NM condition modules within HealthPathways, or PrimaryCare Sidebar.
- Examine opportunities to work with HealthDirect to improve access to specialist clinics, to:
  - link to advice
  - link to a directory of services and accredited clinicians.

### Provide early and ongoing access to respiratory support

- **Scope the development of an ND and NM Portal which could provide accredited training, clinical guidelines and peer networking and collaboration opportunities.**
- Identify obstacles to implementation of recommendations within ACI’s *Domiciliary NIV consensus* statement.44
- Investigate options for linking with and supporting primary care providers. One option for consideration is development of ND and NM condition modules within HealthPathways, or PrimaryCare Sidebar.
## Working together

### Provide seamless coordination of care

- Explore opportunities for Chronic Disease Management and Integrated Care programs in NSW to support management of people with ND and NM conditions. Consider telephone triage and technological solutions for people with ND and NM conditions to improve coordination of care.
- Explore a model at a statewide level to determine where specialist services should be located, and how these should work collaboratively with distant, less specialised service providers (for example, through telehealth).
- Identify primary healthcare providers for each speciality within LHDs to help integrate care of complex patients.

### Plan and coordinate transitions for young people into adult services

- The ACI Transition Network to identify potential obstacles to **Key principles of care for young people transitioning to adult services and possible solutions.**
- Identify well-established transition models and expand to document a model that could be replicated. For example, a modern multidisciplinary transition clinic or an extended transition clinic with a mixed care adolescent clinical nurse consultant. Consider sharing information via an ND and NM Portal.
References

1. Agency for Clinical Innovation. *Care pathways for people with neurodegenerative and neuromuscular conditions diagnostic report.* 2015


22. ACI Palliative Care Network Executive Committee 2014. Ibid


30. Agency for Clinical Innovation. Domiciliary non-invasive ventilation in adult patients. proposal for a new model of care. 2010


