NAI Submission on the Development of a Policy Framework for Medical Card Eligibility to Take Account of Medical Conditions

Overview of this Submission

The NAI welcomes the decision of the Government to develop a policy framework for medical card eligibility to take account of medical conditions. Part 1 of this submission outlines the experiences of people with neurological conditions in relation to the current medical card system, including the importance of the medical card for people with neurological conditions, their experience of the application process and the impact of the review of discretionary medical cards over the past two years. Part II outlines a number of concerns with the proposed system of medical card eligibility being considered by the Expert Panel, which involves developing a list of priority medical conditions. The submission makes a number of recommendations including the need to address the link between access to services and the medical card and the potential to consider an assessment of the impact of illness/disability in awarding medical cards based on medical need, rather than selecting a list of specific medical conditions. Finally, the submission strongly recommends a long overdue review of the long term illness scheme while once more pointing out the challenges associated with a system of eligibility based on selecting specific medical conditions to the potential exclusion of others.

Neurological Alliance of Ireland

The Neurological Alliance of Ireland is the national umbrella body for over thirty not for profit organisations working with people with neurological conditions. It aims to promote the development of services and supports for people with neurological conditions in Ireland through advocacy, policy development, awareness and research.

Neurological Conditions in Ireland

“In Ireland it is estimated that over 700,000 people have a neurological condition affecting the brain and spinal cord. Neurological conditions account for one in eight consultations in primary care and for one in five emergency medical admissions to hospital. They can be difficult to diagnose. They are often long term and disabling. As the population grows and ages the incidence increases. There are a large number of neurological diseases ranging from the relatively common conditions of migraine and epilepsy to rare conditions such as myasthenia gravis and motor neurone disease. They affect all
age groups from the young, economically active adults and older people who are more likely to have neurodegenerative diseases”

| Table 1.1 Estimated numbers of persons with neurological conditions in Ireland |
|---------------------------------|-----------------|-----------------|-----------------|----------------|
| Persons living with the condition | 17% | 725,987 (17%) | 762,960 | 824,743 | 869,143 |
| Help with daily activities | 0.6% | 25,410 (0.6%) | 26,928 | 28,866 | 30,420 |
| Disabled by condition | 2% | 84,699 (2%) | 89,760 | 96,220 | 101,400 |
| Has condition but able to manage life on daily basis | 14.5% | 615,879 (14.5%) | 652,683 | 699,657 | 737,323 |
| Number of newly diagnosed each year | 1% | 43,559 (1%) | 44,880 | 48,110 | 50,700 |
| People caring for person with condition | 1.5% | 61,709 (1.5%) | 66,038 | 70,790 | 74,601 |


**Part 1: Medical Cards and People with Neurological Conditions: The Current System**

There are no statistics available nationally on the percentage of people with a neurological condition in Ireland who have a medical or GP visit card. A nationwide survey of 601 people with neurological conditions and family members carried out by the NAI and published in March 2014 “Living with a
Neurological Condition in Ireland” found that over half of respondents had a medical card and 16% had a GP card.

Table 2: Receipt of Benefits and Entitlements

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No I am not eligible</th>
<th>No I was refused</th>
<th>Applying for at the moment</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP only Card</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with Condition 16%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Member Respondent: 19%</td>
<td>70%</td>
<td>73%</td>
<td>5%</td>
<td>6%</td>
</tr>
<tr>
<td>Medical Card</td>
<td></td>
<td>59%</td>
<td>29%</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>52%</td>
<td>35%</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>77%</td>
<td>12%</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4%</td>
</tr>
</tbody>
</table>

Source: Living with a Neurological Condition in Ireland, 2014, Neurological Alliance of Ireland

The NAI carried out an online survey on medical cards in June 2014 in preparation for the current submission. This online survey, with 148 respondents, examined experiences and viewpoints among people with neurological conditions, family members (responding on behalf of a person with a neurological condition) and health professionals and other service providers. The NAI also held a round table consultation with its member organisations around the issues examined in the survey and the results of this consultation are also documented below under the relevant headings.

Table 3: Survey Respondents: NAI Survey on Medical Cards June 2014

<table>
<thead>
<tr>
<th>Survey Respondents</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with a Neurological Condition</td>
<td>42%</td>
</tr>
<tr>
<td>Family Member responding on behalf of a person with a neurological condition</td>
<td>47%</td>
</tr>
<tr>
<td>Health professional or other service provider</td>
<td>11%</td>
</tr>
</tbody>
</table>

Source: NAI medical card survey: June 2014
(i) Importance of the Medical Card in meeting the costs associated with a Neurological Condition

82% of people with neurological conditions and family members surveyed viewed the medical card as essential for them in meeting the costs associated with having a neurological condition. Only 3% responded that it was not essential.

68% of people with neurological conditions who do not have a medical card struggle to meet the costs associated with having a neurological condition

73% of health professionals and other service providers viewed the medical card as essential in meeting the costs associated with having a neurological condition.

NAI member organisations stressed the level of cost associated with neurological conditions with the high cost of medications, aids and appliances and GP visits.

(ii) Importance of Medical Card in Accessing Health Service

80% of people with a neurological condition and family members who responded to the survey viewed the medical card as essential in accessing health services for their neurological condition.

82% of health professionals and other service providers viewed the medical card as essential in accessing health services for people with neurological conditions.

45% of people with neurological conditions and family members responded that there are services they cannot access because they do not have a medical card.

64% of health professionals and other service providers responded that there are services their clients with neurological conditions cannot access unless they have a medical card.

Health professionals outlined primary care, orthotics, wheelchairs and other equipment and counselling services as examples of services that their clients with a neurological condition cannot access if they do not have a medical card. The importance of counselling and psychological support was highlighted in a recently published study by the Irish Heart Foundation which found that only 11% of stroke survivors were able to access psychological supports\(^2\).

The medical card as a “passport” to services was highlighted as a critical issue by NAI member organisations. There is effectively a dual system of access to services in the community for people with neurological conditions which is having a significant impact on their care.

“People who do not have a medical card cannot access primary healthcare services including allied health professional services in the community”.

The critical need to address this issue is a key point of this submission and is discussed in more detail in Part II of this document.

(iii) Process of Applying for a Medical Card

\(^2\) Experiences and long term needs reported by stroke survivors living in the community (2014) Irish Heart Foundation & Royal College of Surgeons Ireland.
The following responses were provided by people with neurological conditions and family members in relation to applying for a medical card:

“Harrowing, it filled me with fear not knowing if I would get it and thinking if I didn’t get it how was my family going to cope with the costs that lie ahead. It wasn’t clear to me what money I could have and still be eligible. I worked all my life and was used to paying for everything but this disease robs me of everything”

“Very detailed application which hinged on wage only. Difficult to put together”.

“We had to reapply each year as the card was only given on a yearly basis. This was despite having a PROGRESSIVE disease”

“Terrible. Every time we have to appeal. As they are terminal ill they should get one automatically”

The following are some responses from health professionals and other service providers in relation to the application process:

“The process is extremely difficult for many people with neurological conditions particularly if they have cognitive symptoms”.

“Ridiculous, lengthy process met with block after block”

“Medical cards should be issued for longer terms for those with progressive life limiting illnesses”

50% of individuals with a neurological conditions who responded to the NAI survey on medical cards had to appeal the decision in order to secure a medical card.

Consultation with NAI member organisations outlined some of the difficulties with the current application process in relation to people with neurological conditions:

1. People do not recover from neurological conditions but they have to reapply frequently for their card
2. The application process is lengthy and complex, at a time when there is huge stress on the individual and their family
3. The medical card application system is uniform and takes no account of those with rapidly progressing neurological disease
4. The appeals process is now almost a standard feature of applying for a discretionary medical card, resulting in an additional waiting period and further concern and distress for individuals and their families.
5. The application takes into account the financial circumstances but not the costs associated with having a neurological condition. There are a multitude of increased costs of living with neurological disability, from the cost of travelling to appointments and someone having to travel with them, to heating the home, special dietary needs and having to purchase equipment or additional services. The current application process considers only a narrow range of living expenses.

(iv) Impact of the Review of Discretionary Medical Cards
There is evidence that people with neurological conditions have been significantly impacted by the highly publicised review of discretionary medical cards that has taken place within the health services. 15,300 discretionary medical cards were withdrawn between July 2011 and May 2014.

Respondents to the NAI survey published in March 2014 “Living with a Neurological Condition in Ireland” were asked about their experiences of cuts in benefits and entitlements over the past three years. The responses below show a significant number impacted by the withdrawal of their medical card or the failure of their application.

Table 3: Impact of cuts in benefits and entitlements over the past 3 years.

<table>
<thead>
<tr>
<th>Having my medical card taken away from me</th>
<th>Big Effect</th>
<th>Some Effect</th>
<th>No Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21%</td>
<td>21%</td>
<td>58%</td>
</tr>
<tr>
<td></td>
<td>20%</td>
<td>10%</td>
<td>70%</td>
</tr>
<tr>
<td></td>
<td>24%</td>
<td>38%</td>
<td>38%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Being refused a medical card for my condition</th>
<th>Big Effect</th>
<th>Some Effect</th>
<th>No Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>38%</td>
<td>12%</td>
<td>50%</td>
</tr>
<tr>
<td></td>
<td>36%</td>
<td>11%</td>
<td>53%</td>
</tr>
<tr>
<td></td>
<td>44%</td>
<td>13%</td>
<td>44%</td>
</tr>
</tbody>
</table>

Source: Living with a Neurological Condition in Ireland, 2014, Neurological Alliance of Ireland

Health professionals responding to the NAI medical card survey June 2014 noted the following changes in relation to medical cards for clients with a neurological condition over the past 2 years:

70% had noted an increase in withdrawal of medical cards

90% had noted a significant increase in review of medical cards

90% had noticed a significant increase in unsuccessful application for medical cards among people with neurological conditions.

60% had noticed changes in the awarding of discretionary medical cards to people with neurological conditions over the past two years, finding it more difficult to get a person with a neurological condition awarded a medical card on this basis.

One fifth of health professionals and other service providers estimated that 20-50% of their clients with discretionary medical cards had had them withdrawn over the past two years.

Where medical cards had been withdrawn from people with neurological conditions who responded to this survey, 56% had had this happen over the past two years.

“It's much more difficult for these cards to be acquired, people who have an obvious need for them have to be taken through an awful complex system and at the end of it are often refused the card”

“Fewer cards awarded, more restrictive view of conditions, more people are being forced to appeal decisions and under stress because of what is happening”.
82% of people with neurological conditions and family members who responded to the survey felt that people with neurological conditions should have an automatic entitlement to a medical card. For health professionals and other service providers, 45% felt that people with neurological conditions should automatically be entitled to a medical card. 56% responded that they should get a medical card based on the level of expense associated with having their condition. In their comments, health professionals noted the importance of being eligible for a medical card based on medical need (as well as financial means) and the need to ensure that access to certain health services was not limited to medical card holders.

91% of the health professionals and other service providers who responded to the NAI survey felt that the long term illness scheme should be reviewed as part of the current proposed changes to medical card eligibility to reflect medical need as well as financial circumstances. There are a significant number of neurological conditions which are not on the long term illness scheme despite the fact that they are both long term and disabling. Examples include myasthenia gravis, dystonia, acquired brain injury, post polio, motor neurone disease, migraine and Huntington’s disease.

The long term illness scheme has not been revised since the 1970s despite repeated calls from organisations representing people with long term medical conditions, including NAI member organisations. The scheme is discriminatory, with an individual unable to access the scheme if their condition is not listed, regardless of their level of medical need.

Part II: Development of a Policy Framework for Medical Card Eligibility to Take Account of Medical Conditions. Consideration of the Current Proposals

The NAI welcomes the overall aim of reforming the current criteria for medical card eligibility to take account of medical need. This has been promised for some time by successive governments. Towards 2016, the Ten-Year Framework Social Partnership Agreement committed to review “the eligibility criteria for assessment of medical cards in the context of medical, social and economic/financial need”.

However, the NAI has a number of concerns in relation to the proposals that have been outlined:

1. Restricting the range of medical conditions for medical card eligibility based on medical need will lead to the exclusion of other conditions. There is significant risk that many, if not most, neurological conditions will be excluded under such a system
   (a) Many acquired neurological conditions are poorly understood in terms of their impact on the individual and the costs associated with living with the condition.
   (b) Eligibility based on a list of accepted medical conditions does not take into account the variation of need that may occur within the population of those with the neurological condition and may exclude individuals with a high level of need whose neurological condition is not included on the list.

(c) The proposed system links medical need to a clear diagnostic category. For individuals with neurological conditions, a high level of medical need may occur in the absence of a single clear diagnosis or while waiting for a diagnosis to be confirmed.
(d) A high level of medical need may arise from complications or co-morbidity, neither of which will be reflected in a system of eligibility where some conditions receive priority and others are excluded.

2. There are no proposals in the terms of reference of the Expert Panel to review the Long Term Illness scheme
3. Identifying a list of medical conditions in priority order could lead to a further narrowing of eligibility if the decision is made to further restrict automatic eligibility to those conditions highest on the list. This could happen in an environment of increased budgetary pressures on what is a demand-led scheme.
4. The Expert Panel has not been tasked with reviewing aspects of the medical card system that impose significant hardship, including aspects such as delays in processing applications for those with rapidly progressing illnesses and frequent reviews for those with a long term illness.
5. Does the potential exist for a list of prioritised conditions to be open to challenge? What transparency will exist as to the criteria put in place to select a range of medical conditions for automatic entitlement and how this decision was reached by the Expert Panel?

Reform of the Medical Card System: Recommendations for Consideration

The NAI wishes to make a number of recommendations in order to address some of the challenges experienced by people with neurological conditions in relation to the current medical card system.

1) The need to decouple the link between medical cards and access to health services

“Medical card ineligibility can present a serious barrier to accessing services in the community and to being able to live well with a neurological condition”. (Strategic Review of Neurology and Neurophysiology Services Draft report to the National Hospitals HSE 2007)

As outlined earlier in Part 1 Section (ii) of this submission, the medical card currently acts a gatekeeper to a range of essential community based services for people with neurological conditions. Access to these services is based on having a medical card rather than entitlement based on medical need. This results in a situation where people with neurological conditions effectively cannot access these services if they do not have a medical card or if they only have a GP visit card. It is critical this access barrier is addressed and the most effective way would be to decouple the link between the medical card and access to the range of public health services.

The current situation, where people with neurological conditions cannot access certain health services in the community impacts on the level and quality of care they can receive. If they are forced to pay privately for therapy services for example, they incur significant costs and are also excluded from the multidisciplinary team based approach to the management of their condition available in the public system and linked to the care they receive in the hospital. The NAI survey “Living with a Neurological Condition in Ireland” published in March 2014 found that up to 40% of people with neurological conditions were paying privately for certain therapy services including physiotherapy.
While equipment and other medical and surgical supplies may be covered under other schemes, assessment for these needs is critical, not having a medical card can act as a barrier to accessing this assessment by a health professional working in the public health system who can link with their colleagues both in the hospital and community.

A critical issue in relation to medical cards for people with neurological conditions is therefore one of basic access to avail of critical health services. As one health professional noted; “My patients need a medical card to access health services, regardless of their means. Securing a medical card is the only effective way currently to access a range of health services in the community”.

The quote at the beginning of this section is from the strategic review of neurology and neurophysiology services carried out by the National Hospitals Office (2007). This report noted the barrier that medical card eligibility represents to accessing community services for people with neurological conditions. The effects of lack of access to community supports were clearly identified in the report, resulting in increased dependence on hospital based neurology services which are already overstretched.

“Community rehabilitation centred on a person’s home and employing the full range of disciplines can provide cost effective services that help people reintegrate into the community. Increased independence can mean lower care costs overall. Improved well-being and adjustment lessens the burden on carers and reliance on services, prevents unnecessary hospital admissions and can lead to substantial savings over the long term”

The terms of reference of the Expert Panel task this committee to “identify and examine medical conditions, the treatment and management of which, would benefit most from access to services currently only made available to persons with full medical card eligibility”. We take this to imply a recognition of the current situation of limited eligibility to certain health services based on having a medical card.

Change is required to decouple this link between having a medical card and being able to access to certain health services in order to implement Government policy for the development of much needed neurorehabilitation services in the community. The implementation of the National Policy and Strategy for the Provision of Neurorehabilitation Services will necessitate this situation to be addressed in order to ensure that rehabilitative supports can be delivered in the community to those with neurorehabilitation needs. It is difficult to understand how this could be implemented under the current system, where access to a range of community supports critical to the neurorehabilitation process are limited to medical card holders.

The rollout of the independent assessment of need under the 2005 Disability Act (currently only in place for children under 5 years) will also require the health service to address this issue of accessibility to health services based on medical card eligibility.

In its recent submission on the proposed framework for Universal Health Insurance, the NAI raised the issue of access to certain health services based on having a medical card and noted that it was not clear in the proposed framework how the issue of limited eligibility to certain health services based on medical card entitlement was going to be addressed.

---

As a basic point, it is unclear how the current inequities in social care will be addressed under the proposed framework. Currently, availability of a medical card acts as a vital “passport” to a range of community care services for people with a chronic illness or disability. Is this situation likely to change as a result of UHI as many of these services lie within social care? Will there be a universal entitlement to these services based on need?

2. Consideration of an “Impact of Illness” assessment for medical card eligibility based on medical need

The NAI recommends that the Expert Panel consider an impact of illness/disability assessment as part of the application for medical cards which are awarded based on medical need. This would allow (a) level of medical need rather than a specific medical condition as the criterion for eligibility (b) entitlement for a medical card based on medical need would not have to be limited to a number of medical conditions which has the potential to discriminate among those who have a high level of medical need but whose condition is not included in a list of conditions for eligibility (c) the individual could be considered for eligibility based on medical need even if a diagnosis is unclear or has not been made (c) the cost of living associated with a medical condition could be accurately reflected in terms of the expenditure required to support living with the condition (additional transport costs, heating, dietary requirements, equipment etc.). This would also assist those with rare conditions or where there is limited awareness of the impact of the condition. This is the experience of many people with neurological conditions applying for a medical card who feel that there is little understanding or awareness of their condition and the impact in terms of service need and financial burden. (d) This process would provide a clear and transparent system for awarding a medical card based on medical need rather than a restricted range of conditions which could lead to a similar situation to the Long Term Illness Scheme (groups representing people with specific conditions having to campaign and still not securing recognition for the needs of those they represent and also that that a restricted list of conditions could be open to challenge). It is vital that any impact assessment of this kind would facilitate the input of medical and other appropriate expertise in relation to the impact of the condition. Currently, neurologists and other specialists write a letter to accompany a medical card application. This approach would standardise the information available to the HSE in relation to the impact of the medical condition on the individual. The assessment process should be sufficiently comprehensive and informed to take account of episodic & relapsing neurological conditions and the associated fluctuations in illness/disability as well as the cognitive and behavioural impact of a neurological condition (physical mobility and disability issues tend to be prioritised in other standardised assessments in place, for example for the Department of Social Protection schemes). It is also imperative that the thresholds for this assessment would be set at an appropriate level, particularly in view of the potential pressure to restrict eligibility based on resources available. An equitable system of review and appeal should be available which recognises that medical needs associated with many neurological conditions increase over time.

3. Changes to the administration of the medical card system

The consultation carried out by the NAI in order to inform this submission found that the current application and review system imposes considerable stress and hardship on people with neurological conditions. In particular, the review process for those with long term and/or life limiting neurological conditions presents a significant requirement when the circumstances of their illness have not changed. Those with progressive neurological disease face great difficulty in waiting for their application to be processed, especially if they face an appeal.
A policy framework for medical card eligibility based on medical need should include consideration of changes to the administration process to reflect the impact of the current system on chronically ill and disabled individuals and their families.

The steps undertaken by the HSE in 2012 to simplify the renewal process as outlined below should in the immediate term be extended to all card holders of a discretionary medical card:

“Furthermore, the HSE has simplified the renewal process for all medical card holders over 66 years irrespective of circumstances, and all medical card holders under 66 years who originally qualified on the basis of a means test only. The change means that reviews for those medical card holders now operate on a self-assessment basis, as currently happens with the over 70’s. A medical card holder is only required to tick a box and sign a form to confirm that their circumstances have not changed. This new simplified process applies to about 80% of all medical card renewals”6.

4. A Review of Long Term Illness Scheme

The relevant Government Minister noted on 23rd November 2013 that there “are no plans to extend the list of conditions covered by the Long Term Illness Scheme. This was reiterated on 4th February 20147.

The Programme for Government signalled the intention to provide universal access to GP care free at the point of use. The initial intention was to prioritise people with serious medical conditions and the Long Term Illness Scheme would provide a basis for this. However, legal advice from the Attorney General’s office was that this would be subject to challenge, the list of conditions covered by the Long Term Illness Scheme is not based on any objective criteria or evidence. Rather, it reflects political choices made over the years to include some conditions but not others. The office of the Ombudsman has also raised issues in relation to the administration of the scheme around the country8.

The scheme provides critical support to people with disabling conditions such as multiple sclerosis and epilepsy which are covered, but does not extend to cover those living with a wide range of other serious neurological conditions.

Any review of the long term illness scheme should ensure that those who need this support should be able to avail of it.

The NAI has concerns in relation to a number of potential scenarios:

6 Primary Care Reimbursement Service: Medical Cards (June 2012) Health Services Executive Report for the Public Accounts Committee
7 http://www.kildarestreet.com/wrans/?id=2013-11-20a.583
http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/dail2014020400033

8 Local Rules for National Schemes: Inequities in the Administration of the Long Term Illness Scheme (January 2014) Office of the Ombudsman
(a) the long term illness scheme will not be included in the current review of medical card and people living with non-qualifying neurological conditions will continue to be excluded

(b) A decision is made to widen the Long Term Illness scheme but only to those conditions which have been prioritised by the Expert Panel. For a number of reasons outlined earlier, this is likely to exclude many neurological conditions

(c) It is vital that any review of the long term illness scheme widens eligibility to those who need the support. No one with a neurological condition who currently benefits from the scheme should lose this crucial support based on any review of the scheme.

Below is a list of member organisations of the Neurological Alliance of Ireland. The NAI recommends that the individual submissions of our member groups receive careful consideration as they outline in detail the experiences and requirements of those with specific neurological conditions which cannot be adequately reflected in this submission.

**List of NAI members**
Acquired Brain injury Ireland
Alzheimer Society of Ireland
Aware
Epilepsy Ireland
Cheshire Ireland
Chronic Pain Ireland
Dystonia Ireland
Enable Ireland
Epilepsy Care Foundation
Headway
Huntington’s Disease Association of Ireland
Irish Heart Foundation
Irish Hospice Foundation
Irish Motor Neurone Disease Association
Meningitis Research Foundation
Migraine Association of Ireland
Move4Parkinsons
Multiple Sclerosis Society of Ireland
Muscular Dystrophy Ireland
Neurofibromatosis Association of Ireland
North West MS Therapy Centre
Parkinson’s Association of Ireland
Post Polio Support group
Syringomyelia Support group of Ireland
Spinal Injuries Ireland
Spina Bifida Hydrocephalus Ireland
The Rehab Group
Volunteer Stroke Scheme

**Associate Members**

12
Brain Tumour Ireland
PSPA Ireland
Irish Association of Speech and Language Therapists
Irish Institute of Clinical Neurosciences
Myasthenia Gravis Association of Ireland
Irish Society of Physicians in Geriatric Medicine