

Report of the Expert Panel on Medical Need for Medical Card Eligibility

SEPTEMBER 2014



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FOREWORD BY THE DIRECTOR GENERAL OF THE HEALTH SERVICE, MR TONY O'BRIEN

Under the Health Act 1970 (as amended), eligibility for health services in Ireland is based primarily on residency and means. In June 2014, the Government decided to examine options to develop a policy framework to govern eligibility for health services. The HSE was requested to establish an expert panel to examine the range of conditions that should be considered as a basis for eligibility of a range of health services and seek to prioritise such conditions. This report represents the culmination of the panel's deliberations, informed by national and international evidence, expert opinion and a public consultation process where the views of patients, patient representative groups and professional bodies were sought.

I wish to thank Professor Frank Keane, Chair and Dr Alan Smith, Vice-Chair of the multidisciplinary expert panel for producing this *Report of the Expert Panel on Medical Need for Medical Card Eligibility* in a very short period of time. I would like to join with the Chair and Vice-Chair to add my gratitude to all the stakeholders involved. I would especially like to thank the members of the public, patient representative groups and patient advocacy groups for giving up their time and providing the information needed to ensure that a comprehensive picture of Medical Card eligibility in Ireland was captured.

The report makes a substantial contribution. It proposes improvements to the current system, calls on us to strengthen the assessment and measurement of the burden of disease, and to develop our governance structures by establishing a Strategic Clinical Advisory Group. Implementation of the recommendations will increase confidence that we are optimising the use of resources in a fair and equitable manner.

MR TONY O'BRIEN

FOREWORD BY THE CHAIR OF THE EXPERT PANEL, PROFESSOR FRANK KEANE

The Expert Panel was appointed by the Director General of the Health Service Executive, and it was with some foreboding that I agreed to chair this eclectic but distinguished group (see Appendix 2). Over the course of the summer months we had four fairly demanding meetings, interspersed with substantial reading and study material. Despite the intervening holiday period, we believe we have managed as a group to bring together and agree a document which sets out to address some of the difficult and challenging issues around primary healthcare reimbursement and support in Ireland.

I am enormously grateful to all the members of the panel for their always helpful and constructive inputs, their patience and their steadfast endeavour in seeing the job through. I am particularly grateful to Dr Alan Smith, Vice-Chair, for the huge contribution he has made, not only to the choreography of the meetings, but also the great time and commitment he has given to the preparation of the document. He has been a pleasure to work with.

The second chapter written by Dr Deirdre Madden, Faculty of Law, University College Cork, 'Ethical Perspective', deserves all our thanks for this contribution, which from the start moderated our thought and judgement processes in a timely and reflective manner.

Our thanks also to Professor Anne Hickey and Mary-Ann O'Donovan and their team in the Division of Population Health Sciences, Royal College of Surgeons in Ireland for the summary that they provided from their analysis of the online submissions to the public consultation process. Thanks also to Dr Marie Eagleton for her summary of the written submissions from patient representative groups. Both of these are contained in Chapter 4, while the full documents will be published on the HSE website. The Health Service Executive National Patient Advocacy Unit provided a summary of the Patient Representative Forum held in Dublin in August, which is also contained in Chapter 4. We are grateful for this. On behalf of the Expert Panel, I would like to thank the public and patient representative groups alike for their very significant, caring and thoughtful inputs.

Finally, a document such as this could not have been compiled without the substantial support that we have received from the Director General himself and from his office, particularly from Joan Gallagher and Jim O'Sullivan. We were also greatly helped by John Hennessy, National Director of Primary Care, and his team, including members of the Primary Care Reimbursement Service (PCRS), Ivan McConkey and others. Last, but by no means least, I would like to acknowledge Helen Kelly not only for her general helpfulness and valued opinions but also for her fastidious record and minute keeping.

PROFESSOR FRANK KEANE

EXECUTIVE SUMMARY

The General Medical Service (GMS) scheme governs access to Medical Cards in Ireland. The legislative basis for entitlement to Medical Cards is Section 45 of the *Health Act 1970*. Legislation governing the award of Medical Cards does not mention the terms *Medical Card* or *discretionary Medical Card*, but describes people who have *full eligibility* for health services. Current legislation requires that an individual's income and expenditure (i.e. their overall financial situation) must be taken into account during the assessment process.

Controversy arose over the withdrawal and subsequent re-instatement of a number of 'discretionary Medical Cards' during the course of 2012-14. Contributory factors included a long-established political and public level of dissatisfaction with the Medical Card system, its perceived complexity and operational inefficiencies; a general lack of understanding of the term 'discretionary' in the context of Medical Cards; inconsistency in the assessment for Medical Card eligibility; the evolution over the last 30-40 years of the Medical Card as a valuable asset to obtain and then retain; the inflated value of the Medical Card arising from the automatic entitlements to a range of non-medical benefits; and a lack of appreciation of predictable consequences arising from the 2011 centralisation of the administration of the GMS scheme to the Primary Care Reimbursement Service (PCRS).

In July 2014 the Health Service Executive (HSE) commissioned three projects: (i) An Expert Panel to firstly address the fundamental question, '*Can medical conditions be listed in priority order as to their suitability for Medical Cards?*', and secondly, to provide a contemporaneous overview of the Medical Card system; (ii) a public and patient group consultation process; and (iii) a review by Prospectus and Deloitte of the HSE Primary Care Reimbursement Service (PCRS) and its specific role in the management of the Medical Card system. The outputs of the first two of these projects are presented in this report prepared by the Expert Panel.

Media analysis of situations reported on during the Medical Card controversy during 2014 clearly demonstrated a bias towards certain named conditions. Yet, there are many conditions that can be very disabling and equally deserving – but do not have a 'voice' or 'face' in the consciousness of elected representatives, the public or the media – such as very rare diseases, schizophrenia and other mental health conditions. There are also situations when a patient has a disability or impairment that does not necessarily have a specific name or diagnosis, such as the frailty associated with simply growing old.

Many of the respondents to the public and patient consultation process indicated that the current system for allocation of Medical Cards did not discern the true cost of chronic illness. Many patients

with chronic conditions, who do not have Medical Cards, pay up to the maximum for prescription drugs every month (€144) and visit GPs more frequently than normal, which causes undue financial hardship. In addition to paying the maximum for prescribed medication, some patients may often have to pay for other therapies.

There is a desire from the public to see Medical Card eligibility based on the existence of a condition which gives rise to a specified level of medical need and an assessment of how that condition impacts their lives, rather than an automatic right to a Medical Card on the basis of having a particular condition. The public also recognises that having a Medical Card is a gateway to other non-medical services and that some individuals fear loss of their Medical Card because access to these other benefits may then be lost. The public have expressed the view that the issuance of Medical Cards should be for medical benefit and should be decoupled from other non-medical benefits.

There appears to be an inconsistent interpretation and understanding of the requirement to have a Medical Card to access community primary care services such as physiotherapy, occupational therapy, speech and language therapy, public health nursing etc. The use of a Medical Card as the qualifying criterion or allocation mechanism for access to aids and appliances inevitably means that there is inaccessibility for non-Medical Card holders who have potentially greater clinical need.

The request for and scrutiny of personal financial data can be an upsetting exercise for individuals being assessed and reviewed for Medical Cards, but it nonetheless remains the only mechanism available to the health service to fairly and equitably assess undue hardship. Furthermore, a review of the approach taken in other European countries has confirmed that there is no ideal system for assessing the medical burden of disease other than by financial means, with variations including the capping of out-of-pocket expenses, co-payments or some form of universal health coverage.

The advantage of a means test approach is that it is objective and avoids the many difficulties inherent with the subjectivity of making expert judgements of the impact of a disease on the patient and their family. The means test approach can also accommodate and respond to the clinical reality that the severity and impact of a particular condition may change over an unpredictable period of time.

Although imperfect, the current granting of Medical Cards on a discretionary basis does work to a certain level, and cards are awarded on this basis whenever it is possible to do so. The Comptroller and Auditor General's *Report on the accounts of the public services 2012* (published September 2013) reported that in the majority of cases, the cards were awarded on the basis of significant expenditure in relation to medical costs.

The eligibility criteria for a Medical Card, as well as other Primary Care Schemes and their application processes, have evolved over time in a fragmented manner, and have become complex and poorly understood by patients, medical staff and administrators alike. It is inevitable that this has contributed to confusion reflected in the public irritation that has particularly resulted from the 2011 centralisation and standardisation of the PCRS Medical Card renewal, and the current review and appeals processes. This frustration is further evidenced by the sheer volume of phone calls, enquiries and Parliamentary Questions received by the PCRS on a daily basis – a workload that diverts scarce resources away from the processing of Medical Card applications, and which is simply unsustainable and inefficient.

Centralisation of the Medical Card application process into the PCRS has reduced what was an unacceptable level of operational variability and will continue to accrue benefits, provided that satisfactory communication systems are set up with Local Health Offices, GP practices, the public and elected representatives. The PCRS finds itself in the difficult if not invidious position of responding to calls for the provision of a more compassionate service while at the same time being pressed by the Comptroller and Auditor General to incorporate more scrupulous auditing and review processes on behalf of the taxpayer. A careful balance is required between guarding against inefficient State spending with the loss of an individual's rightful entitlement.

There is clearly a societal desire to exercise more compassion and to recognise and support those coping with specific difficult circumstances arising as a result of financial and/or medical hardship, which should be accommodated through a more explicit discretionary process.

To address this desire the Expert Panel recommends that:

1. In the absence of international objective and reproducible methods of measuring burden of disease and illness, it is neither feasible nor desirable to list conditions in priority order for Medical Card eligibility. A listing approach risks inequity by diagnosis and a further fragmentation of services.
2. In the context of an ethical approach to the allocation of finite resources, the current system as it stands is not without its merits for the great majority.
3. The operational deficiencies which currently exist are addressed using an ethical principles framework approach. There are opportunities for significant improvements in the current system using this approach to (a) ensure that any priority setting process is more transparent; (b) involves all stakeholders; (c) delivers similar outcomes for those in broadly similar circumstances; (d) takes account of health outcomes in the context of a finite health budget,

and (e) is sufficiently flexible and attentive to the most vulnerable individuals and those with critical needs.

4. The calculation of financial hardship or means testing should be the primary responsibility of a Government Department or body other than the health service.
5. The role of the health service would appear to be more appropriately qualified to use third-party provided means-tested information, and to define and then identify 'medical hardship' or 'burden of disease'.
6. The governance structure of the PCRS should be published. It should detail responsibility and accountability structures for the administration of the Medical Card Scheme.
7. The separation of the PCRS Medical Card Scheme from the PCRS re-imburement [of Primary Care Contractors] function should be considered.
8. Financial hardship or means testing should remain the main discriminator for selecting the large majority of those eligible for a Medical Card, which is consistent with other health systems in the European Union.
9. Where possible, the Medical Card system should be made simpler and more explicit, and there needs to be a comprehensive suite of communication and education materials to assist individuals and healthcare professionals with the Medical Card application process and the concept of renewal.
10. Non-medical benefits should be uncoupled from Medical Cards. Access to these non-medical benefits should, however, remain as a means-tested support, but should not be an automatic entitlement determined by an individual's Medical Card status.
11. Access to primary care services (physiotherapy, occupational therapy, speech and language therapy, public health nursing etc.) should be consistent across the country. Prioritisation should be on the basis of clinical need – independent of the possession of a Medical Card – defined after triage into categories of urgent or routine, and thereafter seen in chronological order within these categories.
12. An individual's Medical Card status should not be the sole qualifying criterion for access to aids and appliances.
13. For individuals awarded a Medical Card incorporating 'discretion', the renewal process needs to be handled with a greater degree of sensitivity.

14. As a working principle, discretionary Medical Cards should only be provided to the individual with the index condition, and not to the entire family.
15. If a discretionary Medical Card award involves any terminal or life-limiting condition, such as motor neurone disease, then it should be granted for the remainder of life, and should not require the individual or their family to undergo a standard review process every three years.
16. Society's desire to exercise a more compassionate and supportive approach for those with a combination of financial and/or medical hardship should be addressed by extending the discretionary decision-making process beyond financial hardship to include an assessment of the burden of a medical condition(s).
17. The general population should be involved in deliberating on the ethical and social issues arising from access to healthcare in the context of finite resources.
18. A new Strategic Clinical Advisory Group should be incorporated into the PCRS governance structure, with broad and experienced clinical, lay and administrative representation and access to expert opinions when required. It is the view of the Expert Panel that this is required in order to give clinical oversight and guidance to the operation of a more compassionate and trusted Medical Card system which can strive to ensure that the relatively small percentage of cases requiring the recognition of the burden of a medical condition(s), over and above financial hardship, can be accommodated.
19. The initial work programme for the Strategic Clinical Advisory Group should firstly address the development of a strategic framework for assessment and measurement of the burden of disease; secondly, the development of appropriate operational guidelines for Medical Assessors and Decision Officers and, thirdly, the development of appropriate key performance indicators (KPIs) to support clinical oversight and performance assurance.
20. The significant challenges to be faced in extending the discretionary decision to include an assessment of the burden of a medical condition(s) must be acknowledged by all. These include the fact that professional judgement in the assessment of medical hardship can never be completely objective, fully transparent and totally reproducible; the methodology to underpin an enhanced discretionary process requires an options appraisal of existing measurement and disability comparators, and proxy measures of the burden of disease including healthcare consumption; a realistic timeframe to examine the feasibility and costing of such a process; and finally, the additional resourcing that will be required to increase clinical

assessment capacity, including doctors, nurses and allied health professionals, in order to provide a greater degree of scrutiny and personalised clinical judgement.

21. In terms of maximising population health gain, a priority for the health service should be to use the preceding recommendations as a stepping stone to the implementation of the first phase of the Government's Primary Care reform programme, providing free GP care for all, with the aim of further ensuring universal access to the full spectrum of Primary Care Services as a matter of course and thereby aligning the health service in Ireland with health systems in other EU Member States.

22. An annual report of the implementation status of each of the recommendations contained in this report should be presented by the HSE National Director of Primary Care to the Director General of the HSE.

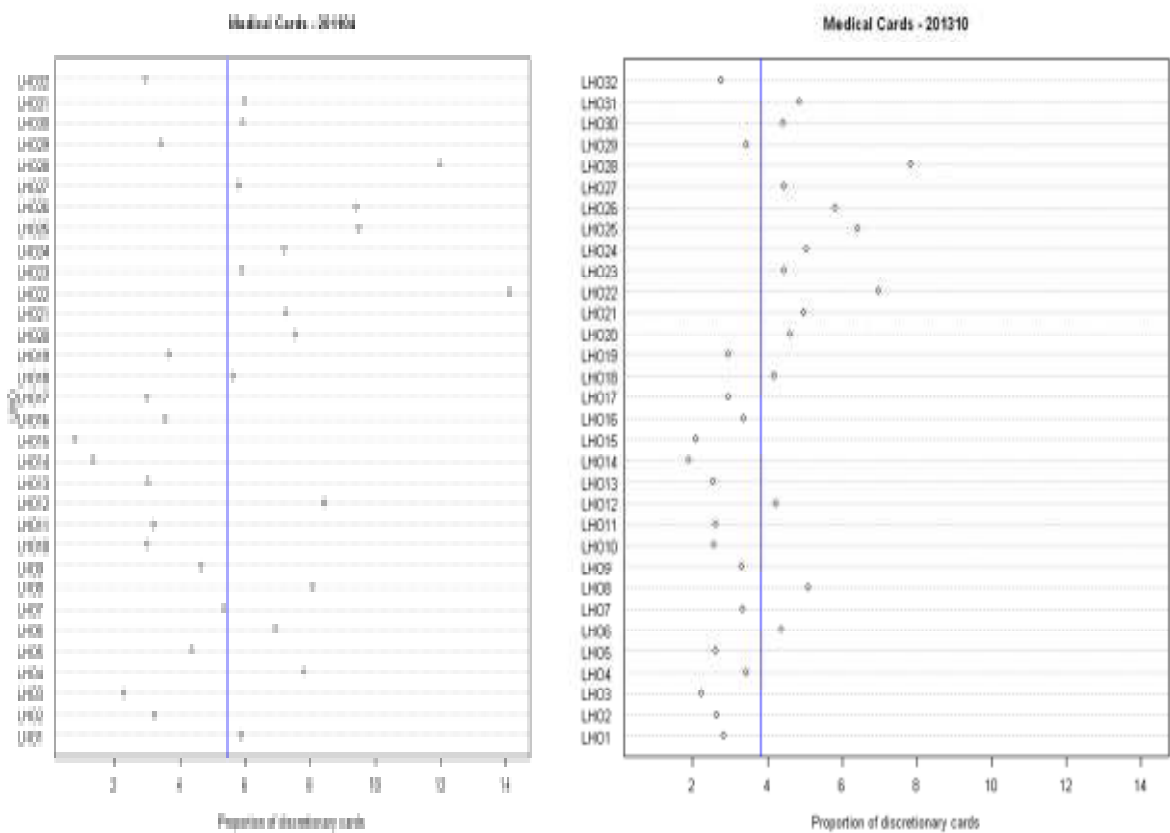
1. INTRODUCTION

- 1.1 Ideally, a national health service should be free at the point of use, meet the clinical needs of everyone, be comprehensive and integrated in the services it delivers, and provide support, education and care that is evidence based and outcome validated. This is a tall order for any national government and is probably not fully achievable.
- 1.2 The General Medical Service (GMS) scheme governs access to Medical Cards in Ireland. Eligibility criteria are set out in legislation and have traditionally been based on income thresholds since the 19th century, when Poor Law bodies took over the dispensary system and provided free services for those who were unable to pay for them. Although there have been various amendments and reforms of the system since that time, the basic premise has remained the same i.e. that the State has an obligation to provide general medical services for those who are unable to pay for them through their own means. In addition to setting specific income thresholds for specified categories of persons who are eligible to receive listed services, there has also traditionally always been a discretion vested in the Local Health Offices/Health Boards to grant Medical Cards in cases of particular hardship to those who would otherwise be ineligible.
- 1.3 Up to July 2011, the issuance of Medical Cards was administered in approximately 100 Local Health Offices, reflecting the former health board structure. A key risk in any such decentralised administration system is unaccountable inconsistency or variability between regions in the application of eligibility rules. While the Medical Card Scheme had been the basis for the delivery of the majority of primary care services in Ireland for over 40 years, there was clear evidence that assessment for eligibility for Medical Cards was not consistent between the 100 Local Health Offices conducting the reviews, with some card holders granted Medical Cards for long periods, in some cases up to 20 years.
- 1.4 In consultation with the Department of Health, the HSE decided that fundamental change in the administration of the scheme was required if the inefficiency and lack of transparency and consistency was to be addressed. Since 1 July 2011, card issuance has been managed centrally within the HSE Primary Care Reimbursement Service (PCRS). The objective of the centralisation process was to provide for a single, uniform system for Medical Card applications and renewals, replacing the different systems previously operated in the Local Health Offices; streamline work processes and implement process improvements, resulting in more efficient

processing; reduce the number of staff required to process applications and renewals; improve customer services and over time; ensure a more accountable and better managed Medical Card processing service.

- 1.5 There is evidence that the wide variation in assessment for Medical Card eligibility has reduced, and that an appropriate level of transparency, consistency and equity is appearing. See Figure 1.

Figure 1 Variation in assessment of Medical Card eligibility before and after administrative centralisation



- 1.6 Although the centralisation of administration of Medical Card eligibility assessment has allowed the introduction of a uniform system for assessment of eligibility, it was somewhat inevitable that such a large system, and indeed cultural change over a relatively short time period, would result in a certain level of non-renewal amongst Medical Card holders. The issue of Medical Cards has come to the fore this year, triggered in part, it appears, by the level of non-renewal amongst Medical Card holders, and in particular the non-renewal of Medical Cards that had been issued on the basis of discretion. This has caused significant upset and disquiet.

- 1.7 In the context of discretionary Medical Cards, the upset and disquiet has been exacerbated by an inherent level of massive variability in their award across the 26 counties, ranging from 3-12/100,000 population to 39-53/100,000 population.¹
- 1.8 In its report to the Committee of Public Accounts in June 2014² the HSE explained that planned expenditure (2014) in the delivery of primary care services across 12 community health schemes, including the Medical Card Scheme, to the entire population would amount to approximately €2.4 billion, involving approximately 80 million transactions delivered to more than 3.4 million eligible persons.
- 1.9 The scale of costs within the Medical Card and Primary Care schemes, as well as the volume of associated transactions, mean that there are areas of risk that need to be managed and controlled. The Comptroller and Auditor General has already reported that the evidence suggests there is a significant level of excess payment in the Medical Card system and the HSE should conduct reviews of random samples of Medical Card holders on an annual basis.³ In the main, excess payment (i.e. ineligibility) arises as a result of changes in the card holder's circumstances over the validity period of the card.
- 1.10 Legislation enacted in March 2013 provides for the furnishing of data by the Department of Social Protection and the Revenue Commissioners to the HSE.
- 1.11 The HSE has implemented a series of control options which comprise a review upon expiration of the defined eligibility period; risk-based reviews based on specific criteria such as inactive cards or where information from other Departments⁴ or bodies indicate that the Medical Card should be reviewed; random review; use of the Death Events Notification System (DEPS), which identifies people who are deceased.
- 1.12 In response to the public disquiet as to the legitimacy and authority of the Medical Card system, a Government decision was taken (July 2014) to restore discretionary Medical Cards to approximately 13,300 people. In addition, the Director General of the HSE commissioned an Expert Panel to attempt to list conditions in priority order as to their eligibility for Medical Cards; he also commissioned a Review of the HSE PCRS by Prospectus and Deloitte.

¹ Personal communication, July 2014. HSE, Office of National Director of Primary Care

² HSE Report to the Committee of Public Accounts on 12 June 2014

³ The Comptroller and Auditor General's *Report on the accounts of the public services 2012* (published September 2013)

⁴ Section 8 Health (Alteration of criteria for eligibility) Act 2013. Legislation enacted in March 2013 provides for the furnishing of data by the Department of Social Protection and the Revenue Commissioners to the HSE.

1.13 It should be noted that the Government announced in 2013 (Budget Day) that all children under the age of six years would be entitled to GP Visit Cards.

1.14 The Terms of Reference of the Expert Panel were:

1.14.1 To advise on the appropriate approach to identify and examine medical conditions, the treatment and management of which would benefit most from access to services currently only available to persons with full Medical Card eligibility.

1.14.2 To devise a framework, incorporating specific criteria which will prioritise medical conditions in terms of the degree of health benefit to the person with the medical condition.

1.14.3 To apply objective medical and scientific evidence during the course of all deliberations, conclusions and recommendations.

1.14.4 To seek advice of other relevant experts as required.

1.14.5 To take into consideration the views of patients, the public and patient representative/advocacy groups, in order to reflect the patient perspective.

1.14.6 Advise on the timeframe for any periodic review of the list of medical conditions proposed.

1.14.7 Advise on the appropriate approach to meet the needs of individual patients with medical conditions of a transient nature.

1.14.8 Provide an initial report to the Director General (DG) to include a list of medical conditions for the DG to present to the Minister for Health and Government.

1.14.9 Report to the Budget Impact Analysis Group and to the Director General.

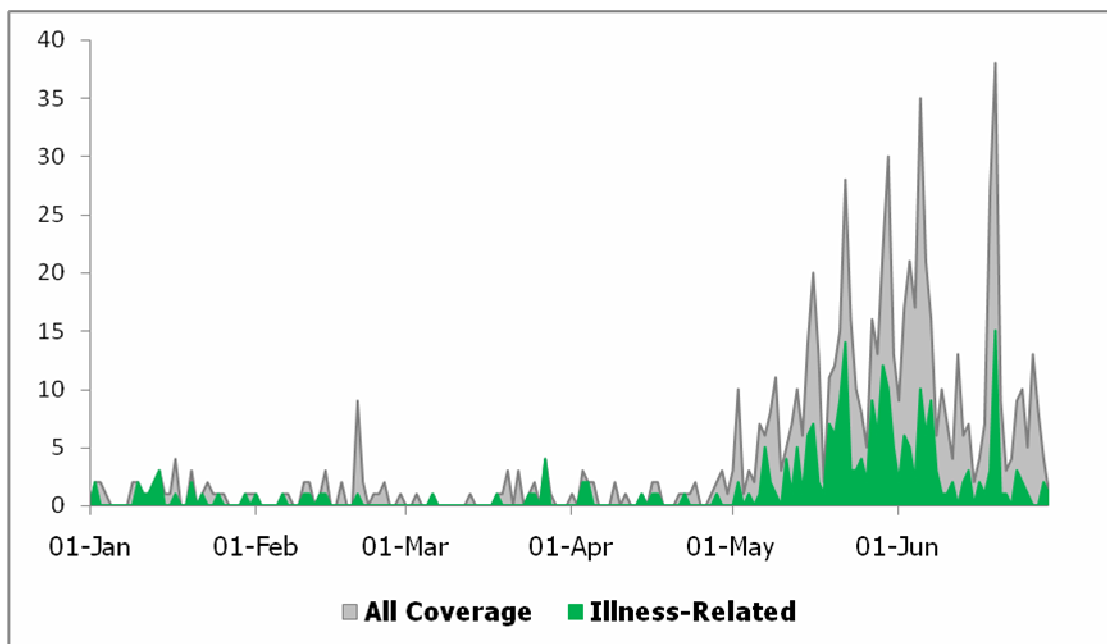
1.15 The Expert Panel, although primarily charged with attempting to list medical conditions as to their suitability for Medical Card, were of the view that this would inevitably result in providing their perspective and commentary on the operation of the Medical Card system. Because of the sheer complexity of the issues involved, the panel believed that an ethical commentary and perspective would provide an important and valuable framework to guide their deliberations, conclusions and recommendations. The Expert Panel's work has also been guided and referenced against the experience in other EU healthcare systems. The Expert Panel was particularly determined to ensure that the views of patients, the public and patient representative/advocacy groups would play a central role in their work.

Medical Cards and media coverage (January-June 2014)

1.16 The Expert Panel examined media coverage of the discretionary Medical Card issue as it evolved over the course of the first six months of 2014.⁵

1.17 Between 1 January and 30 June 2014, a total of 772 articles in the Republic of Ireland press were recorded on the issue of discretionary Medical Cards; the heaviest volumes of articles were recorded in May and June, with 330 and 333 articles respectively (See Figure 2). One-third of all reportage on the matter (equating to 254 articles) referenced a particular illness or condition. May was the heaviest month for references to illnesses or conditions that could be impacted by the loss of discretionary Medical Cards, with 129 articles noted.

Figure 2 Trend in media coverage of medical cards (Jan-June 2014)



⁵ Kantar Media was commissioned to undertake an analysis of media coverage on behalf of the Expert Panel, covering the period January-June 2014.

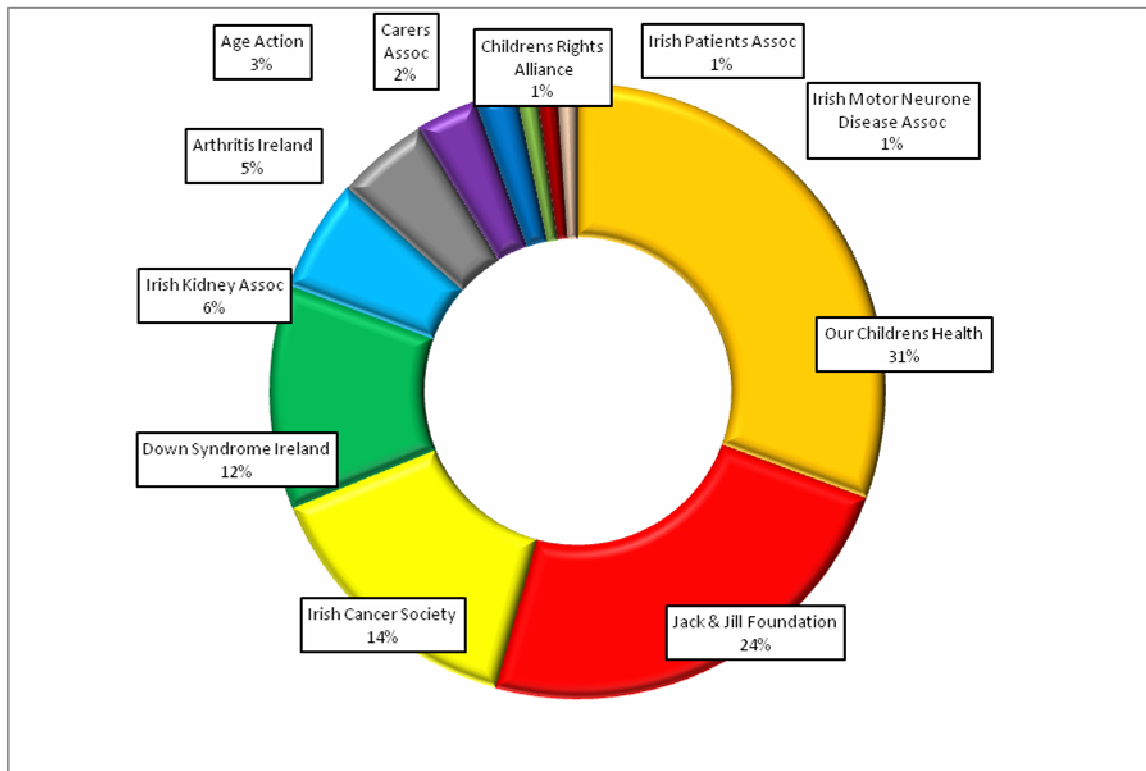
1.18 Down syndrome was by far the most prevailing condition to resonate in the press over the timeframe. References to cancer-related illnesses also substantially permeated the press coverage. See Table 1.

Table 1 **Illness and conditions associated with media coverage (January-June 2014)**

Reported illness/condition	Volume of articles
Down syndrome	106
Cancer	81
Arthritis	29
Leukaemia	29
Cerebral palsy	26
Motor neurone disease	20
Kidneys/dialysis	19
Multiple sclerosis	12
Epilepsy	9
Mowat-Wilson syndrome	9
Asthma	8
Wiedemann-Steiner syndrome	4
KCNQ	3
Narcolepsy	3
Lung transplants	2
Severe global development delay	1
STXBP1	1
Immunodeficiency conditions	1
Parkinson's disease	1
Spina bifida	1
Filamin-A gene disorder	1

1.19 Multiple charities and associations obtained citations in the press in relation to this issue, with the most prolific being Our Children’s Health, the Jack & Jill Children’s Foundation, Irish Cancer Society and Down Syndrome Ireland (Figure 3).

Figure 3 Charities and associations citations in media coverage (January-June 2014)



2. ETHICAL PERSPECTIVE

Relevance of ethics

2.1 Where resources are limited and it is impossible or impracticable to provide universal services, any decision to reallocate resources within the public health system, or to allocate services to one group rather than another, is a decision that must be open to strict scrutiny and accountability. The basic premise of Irish society is that every citizen has fundamental constitutional rights such as the right to life and the right to education, but enforceability of those rights may be contingent on the availability of the necessary resources. When resources are limited, corresponding rights to those resources also become limited. The difficulty lies in trying to ensure fairness and ethical justice in the rationing process. Many criteria play a role in decision-making in this context. As follows:

- The societal wish to maximise general population health
- Distribution of health in the population and redressing inequities; many societies may wish to prioritise vulnerable population groups, such as those in lower socio-economic groups, those with chronic conditions, children, pregnant women and the elderly.
- Specific societal preferences that target preventative over curative treatments, or the provision of acute care in life-threatening situations
- Budgetary constraints and the costs of implementation
- Political criteria such as the influence of interest groups and legacy issues.

2.2 In making such difficult decisions, ethical principles can come into conflict and it becomes necessary to balance competing concerns. There is no national or international consensus on the correct approach to this balancing exercise.⁶ The emphasis in the literature on this issue is on ensuring that the decision-making process itself is fair, open and inclusive of all perspectives. Therefore it is important that the decision-maker is as transparent as possible in relation to the ethical stance taken and the values underpinning the decision.

⁶ The ethical principles adopted by Healthy Ireland in its Framework for Improved Health and Wellbeing 2013-2025 are Equity, Fairness, Proportionality, Openness and Accountability, Solidarity, and Sustainability, <http://www.hse.ie/eng/services/publications/corporate/hieng.pdf>

Principlism

2.3 There are a number of ethical approaches that may be taken to the analysis of healthcare decision-making. These include casuistry (solving cases by referring to paradigmatic cases for which an undisputed solution has already been found), coherence analysis (reflecting on the consistency of ethical arguments or theories without prescribing which arguments are prima facie relevant), interactive (inter-subjective consensus on problematic issues reached through discourse involving relevant stakeholders), or principlism (analytical framework based on common moral principles shared in society). The latter has recognised advantages in that it provides a comprehensive normative framework for ethical analysis rather than just a procedural approach. The application of biomedical principles, in particular those developed by Beauchamp and Childress,⁷ is one of the most frequently used approaches to resolving ethical dilemmas in healthcare.

The Four Principles approach devised by Beauchamp and Childress are as follows:

- Respect for persons (autonomy, ensuring patient understanding, voluntariness, decision-making capacity)
- Beneficence (balancing benefits and harm: risks/costs)
- Non-maleficence (the minimisation of harm to others)
- Justice (the fair distribution of benefits and burdens).

2.4 Although it does not feature in the Four Principles approach outlined above, another important ethical value is that of compassion, which demands that attention be paid to the effects of health inequalities on individuals and families. Inequalities in health are differences in health status or in the distribution of health determinants between different population groups due to the conditions in which people are born, grow, live, work and age. As pointed out by Healthy Ireland, “there is an uneven distribution of the risk factors associated with many chronic diseases, with the burden borne disproportionately by those in the lower socio-economic groups. People with higher socio-economic position in society have a greater array of life chances, more opportunities to lead a more fulfilling life and tend to have better health.”⁸

⁷ Beauchamp and Childress, *Principles of Biomedical Ethics* (1979), now in its 7th ed.

⁸ Healthy Ireland, A Framework for Improved Health and Wellbeing 2013-2025 at page 45
<http://www.hse.ie/eng/services/publications/corporate/hieng.pdf>

2.5 These ethical principles are prima facie binding, meaning that they are always important in every situation, but they are not absolute and may come into conflict with each other. The principles must always be viewed in the context of the specific matter under consideration, and balanced with each other. Balancing principles can be challenging, but it is worth considering that a principle should only be overridden if better reasons can be provided for acting on an overriding principle, and the infringement must be commensurate with achieving the primary goal, negative effects of the infringement are minimised, and the decision is reached impartially.

2.5.1 **Respect for persons** – This includes acknowledging a person’s right to make choices, to hold views, and to take actions based on personal values and beliefs. It is often described as respect for autonomy, which literally means self-rule, in other words making one’s own deliberate decisions. In the medical context, respect for autonomy is of vital significance in ensuring that patients are informed about their choices and asked to make their own decisions about their healthcare. It requires doctors to seek informed consent from patients before any treatment or intervention (except in cases of incapacity or medical emergency). It also requires patient confidentiality to be maintained, appropriate behaviour to be practised and good communication methods to be used between patients and healthcare professionals.

2.5.2 **Beneficence and non-maleficence** – The ultimate aim in healthcare is to produce net benefit over harm, while recognising that inevitably some risk of harm may exist when any medical intervention takes place. Beneficence is the traditional Hippocratic duty to prioritise patients’ best interests, while non-maleficence is the duty not to cause harm or risk of harm to patients. These duties mean, for example, that those who treat patients must be appropriately qualified, as otherwise the risk of causing harm becomes disproportionate. Healthcare professions therefore undertake to provide appropriate training and education to prospective and current practitioners in order to ensure adequate protection of patients.

2.5.3 **Justice** – The principle of justice could be described as the moral obligation to act on the basis of fair adjudication between competing claims. As such, it is linked to fairness, entitlement and equality. In healthcare ethics, this can be subdivided into three categories: fair distribution of scarce resources (distributive justice), respect for people’s rights (rights-based justice) and respect for morally acceptable laws (legal

justice).⁹ In the context of the allocation of resources, conflicts exist between several common moral concerns: to provide sufficient healthcare to meet the needs of all who need it; when this is impossible, to distribute healthcare resources in proportion to the extent of people's needs for healthcare; to allow healthcare workers to give priority to the needs of their patients; to provide equal access to healthcare; to allow people as much choice as possible in selecting their healthcare; to maximise the benefits produced by the available resources; to respect the autonomy of the people who provide those resources and thus limit the cost to taxpayers and subscribers to health insurance schemes. All these criteria for justly allocating healthcare resources can be morally justified but not all can be fully met simultaneously.¹⁰

Justice in access to healthcare services

- 2.6 Clearly, good health is vitally important. We all desire it for ourselves, our loved ones, and indeed for everyone. Few would dispute that access to essential healthcare should not hinge on one's ability to pay. However, "at its most basic level, it is literally impossible for government to guarantee good health to its citizens."¹¹... "Because of resource scarcity, access to healthcare and related technologies in practice hinges not on legal requirements, but on government budget decisions and, at the private level, on clinical judgements of health professionals and the incomes of individual patients. In keeping with their responsibility to provide for the general welfare, governments have much of the responsibility for defining public health objectives for the whole society and providing the resources to achieve them. Those determinations always involve negotiation, trade-offs, and the balancing of interests."¹²
- 2.7 In relation to the issue of access to or allocation of healthcare services, the principle of justice is one of the most important bioethical principles in this balancing of interests and has been addressed in bioethics literature since the 1980s. If we accept that the health system must be sustainable¹³ and that it is impossible for any health system to provide everything for everyone, then setting limits on expenditure of shared societal resources is ethically required and must be done in a just, transparent and compassionate way.

⁹ R Gillon "Medical ethics: four principles plus attention to scope" (1994) *BMJ* 309:184

¹⁰ Gillon, note 4

¹¹ Timothy Goodman "Is there a right to health?" (2005) *Journal of Medicine and Philosophy* 30:643-662

¹² Goodman note 6 at 655

¹³ Healthy Ireland, a Framework for Improved Health and Wellbeing 2013-2025, Appendix 2
<http://www.hse.ie/eng/services/publications/corporate/hieng.pdf>

- 2.8 Rationing¹⁴ is the controlled allocation of some scarce resource or goods. It implies that limits are placed on its availability. In healthcare this applies to treatments, services, pharmaceuticals, medical procedures and so on. When healthcare resources are rationed, patients may be restricted to certain treatments or placed on waiting lists for treatments. It means that someone somewhere has made a decision about the limits of what is provided or how it is provided, i.e. a priority-setting decision.¹⁵ Although rationing of healthcare resources sounds like an unethical proposition, as it interferes with individual choices and values, it is inevitable in all healthcare systems around the world. Indeed, there are those who argue that healthcare rationing is not only necessary but also desirable. “The careful rationing of health care is one of the factors that make a health care system work well. The best health care systems in the world do it.”¹⁶
- 2.9 Hard ethical choices are sometimes masked in clinical or technical terms, as the idea of rationing is unpalatable, unpopular and not politically correct, since it means in reality that some people who may benefit from healthcare may have to do without it. However, it is important to acknowledge that rationing is not limited to State-run or sponsored public health systems, it also takes place in private health insurance and in the most affluent of societies. When the Government decides which drugs to subsidise, it is engaged in rationing; when it decides where to build a new hospital, it is engaged in rationing; when it introduces a cancer screening programme it is engaged in rationing because as a result of those priority-setting decisions, other drugs, citizens and patients will not be funded. Private insurers carry out the same exercises by loading premiums on new entrants with pre-existing conditions, or by agreeing to only fund certain treatments. It is inevitable that some patients will be disadvantaged by the limits that are set in either the public or the private healthcare system. What is crucially important here is that the priority-setting decisions must be reached fairly and efficiently, so that they can be morally justified.
- 2.10 As members of society we are still feeling our way even at the level of defining what the competing moral concerns of justice are. Gillon says we must be particularly wary of apparently simple solutions to what have been perceived as highly complex problems for at least 2,500 years.¹⁷ For example, he refers to populist solutions in distributive justice such as have occurred in Oregon in the United States (see below), and technical and simplistic

¹⁴ Indeed, the word rationing itself is usually avoided, as it raises memories of war-time scarcity and poverty, but it is arguably a more honest and accurate description of the reality of healthcare systems worldwide.

¹⁵ Bognar and Hirose, *The ethics of health care rationing* (Routledge Press 2014) page 1

¹⁶ Bognar and Hirose note 9 at 2

¹⁷ Gillon, note 4

economic solutions such as the system of costed quality-adjusted life years (QALYs) which are tempting in their definitiveness and simplicity; they fail, however, to give value to the wide range of other potentially relevant moral concerns.

How do we set priorities ethically?

- 2.11 Disease and disability, by impairing normal functioning, restrict the range of opportunities open to individuals. Healthcare is special because it protects or tries to restore normal functioning, which in turn protects the range of opportunities open to individuals. Healthcare thus makes a distinct but limited contribution to the protection of equality of opportunity; it preserves for people the ability to participate in the political, social and economic life of their society and sustains them as fully participating citizens.¹⁸ However, although the idea of rationing health services causes political and social discomfort, the reality is that the notion that a State could provide every single intervention that holds even the smallest possibility of clinical benefit to every citizen is financially untenable.¹⁹ The argument that healthcare *should* contribute to equality of opportunity does not provide us with the means by which to address highly contested issues of how to distribute medical goods and services fairly.
- 2.12 There are various approaches in moral theory that one might take to this issue: libertarianism, utilitarianism, egalitarianism etc. Nearly all appear to take the view that just societies should provide all their members with guaranteed access to at least a decent minimum of healthcare, although there is little consensus on what the decent minimum entails.²⁰ Acknowledging therefore that some rationing/priority-setting/allocation decisions must be made, a fair process must be established by which to make such decisions.

The Oregon example

- 2.13 An often-quoted process of healthcare allocation decision-making is the Oregon plan, which took place in the late 1980s following a public outcry after the death of a seven-year-old boy whose bone marrow transplant, which would have cost €100,000, was not covered by Medicaid. The State of Oregon realised that it had to balance costs, benefits and access in the face of scarcity of resources. Either it had to limit the Medicaid programme to the most cost-effective services, or it had to deny healthcare to many people. The State Government

¹⁸ Norman Daniels, "Justice, Health and Healthcare" (2001) *American Journal of Bioethics* Vol. 1 No. 2

¹⁹ Samia Hurst and Marion Danis "A framework for rationing by clinical judgement" *Kennedy Institute of Ethics Journal* (2007) Vol 17, No.3, 247-266

²⁰ Madison Powers and Ruth Faden, "Inequalities in Health, Inequalities in Health Care: Four Generations of Discussion about Justice and Cost-Effectiveness Analysis" (2000) *Kennedy Institute of Ethics Journal* Vol. 10, No.2, 109-127 at 111

decided to develop an open and transparent process for citizens to agree on a list of medical services that would be covered by its Medicaid programme for those below a specified income level. A working group was established and agreed on three important principles:

- Access to a basic level of care must be universal.
- Society is responsible for financing care for poor people.
- A basic level of care must be defined through a public process.

2.14 A panel of experts known as the Health Services Commission was tasked with formulating a list following extensive public consultation which was declared to be the world's first prioritised list of health services.²¹ The first list, which was based on a methodology of cost-benefit analysis, yielded some peculiarities, such as possibly covering tooth caps, but not surgery for emergent appendicitis. The plan was subject to much criticism, due to these anomalies and there was also opposition to the plan on the grounds that it discriminated against people with disabilities. The Commission revised the plan to take these considerations into account, with the result that cost effectiveness was relegated to the back seat.²²

2.15 As an example of the commission's work in rebalancing competing claims, the highest-priority categories 1 through 6 subsequently encompassed services such as the "birth of a child and maternal care" (Category 1); "preventive care;" and "life-threatening diseases," each with many line items in the category, whereas lower-ranked categories included non-fatal, self-limiting, elective, or inconsequential conditions and interventions. The Oregon Health Plan was finally accepted in 1993. Although in many ways an imperfect method, many advocates have noted the importance of the list from an ethical point of view in attempting to develop a fair and transparent consultative public process for prioritising medical services through its laws and regulations.

The National Health Service (UK)

2.16 Another example of how rationing decisions are made in other jurisdictions can be seen in the model adopted in the UK where healthcare is provided by the publicly funded National Health Service (NHS). In England and Wales, decisions relating to access to healthcare are decentralised and services are organised by regional trusts, with the result that there are inequalities between different areas, known as the postcode lottery.²³ Trusts make their own

²¹ <http://www.oregon.gov/oha/healthplan/pages/priorlist.aspx>

²² Bognar and Hirose, note 10 at 61

²³ Bognar and Hirose, note 10, 63-65

decisions about spending and coverage, so a patient may not be covered for an intervention that another patient living in a different area *would* be covered for.

2.17 To reduce this inequity, the government asked the National Institute for Clinical Excellence (NICE) to draw up guidelines for coverage and spending decisions. Its guidelines are based on cost effectiveness analysis, measured by QALYs,²⁴ of *new* medical technologies and treatments and it has not undertaken a systematic review of *all* medical technologies and services. NICE also instituted Citizen Councils, comprised of representatives of the general population rather than experts in healthcare, to deliberate on the ethical and social issues raised by its guidelines. In common with the Oregon Health Plan, this also demonstrates the importance and value of a fair and transparent consultative public process for prioritising payment for medical services.

Conclusion

2.18 Every member of society must have an adequate array of core healthcare benefits; every member of society deserves an adequate level of protection from illness and avoidable pain and suffering related to health conditions. However, this does not mean access to every potentially useful health service, as there are links between access, cost and quality that cannot be ignored. These interconnections must be comprehensively considered, as otherwise they may result in ethical difficulties in terms of reduced overall access, or unacceptable effects on cost and quality.

2.19 The contents and limits must be established through an ethical process – setting limits or ‘rationing’ is difficult, but can be achieved ethically if the following five principles are taken into account:²⁵

1. **Transparency** – the priority-setting process should be transparent to those affected.
2. **Participatory** – the process should involve all stakeholders in the design of the process.
3. **Equity and consistency** – it should result in similar decisions for those in similar circumstances.
4. **Sensitivity to value** – it should take into account net health outcomes of services and the required resources.
5. **Compassion** – it should be flexible, responsive to individual values and attentive to the most vulnerable individuals and those with critical needs.

²⁴ Quality-adjusted life years

²⁵ Ethical Force program of the American Medical Association: <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/the-ethical-force-program/fair-health-care-coverage.page>

3. THE CURRENT MEDICAL CARD SYSTEM IN IRELAND

Legislation

- 3.1 The main legislation on entitlement to Medical Cards is Section 45 of the *Health Act 1970*. This has been amended a number of times.

Section 45, as amended, provides:

(1) A person in either of the following categories shall have full eligibility for the services under this Part—

(a) adult persons, who in the opinion of the Health Service Executive, are unable without undue hardship to arrange general practitioner medical and surgical services for themselves and their dependants,

(b) dependants of the persons referred to in paragraph (a).

(2) In deciding whether or not a person comes within the category mentioned in subsection (1) (a), the Health Service Executive shall have regard to the person's overall financial situation (including the means of the spouse, if any, of that person in addition to the person's own means) in view of the person's reasonable expenditure in relation to himself or herself and his or her dependants, if any.

- 3.2 Of note, the legislation governing the awarding of Medical Cards does not mention the phrase *Medical Cards*. Instead, it describes people who have *full eligibility* for health services.
- 3.3 The health service can exercise discretion when a person does not qualify for a Medical Card under Section 45 (1), but where circumstances would merit the awarding of a card.

Section 45, as amended, provides:

(7) Any person who is not in either of the categories mentioned in subsection (1) but who, in relation to a particular service which is available to persons with full eligibility, is considered by the chief executive officer of the appropriate health board to be unable, without undue hardship, to provide that service for himself or his dependants shall, in relation to that service, be deemed to be a person with full eligibility.

- 3.4 The only criterion used to determine whether or not to provide a Medical Card is based on whether the individual would be unable to provide that service for himself and his dependants without undue hardship. The Act does not provide for further criteria upon which the health service can evaluate what amounts to undue hardship.

- 3.5 The exercise of discretion provided for in Section 45 (7) can only be determined using professional judgement and expertise. Each case must be determined on its merits, using the criteria that are appropriate in each case to decide on the issue of undue hardship.
- 3.6 Any setting of an exhaustive list of criteria or measuring of thresholds might amount to an unlawful restriction of the health service's statutory discretion. As a result, flexibility is required in order to properly assess each case on its merits and evaluate the injustice to the individual against the tangible public benefit if a card is to be withheld.
- 3.7 Entitlement to a GP Visit Card is governed by Section 58 of the *Health Act 1970* (as amended by the *Health (Amendment) Act 2005*).

Section 58 of the Health Act, 1970, as amended, provides:

- (1) The Health Service Executive shall make available without charge a general practitioner medical and surgical service for a person in any of the following categories –*
- (a) persons with full eligibility*
 - (b) adult persons with limited eligibility for whom, in the opinion of the Health Service Executive, and notwithstanding that they do not come within the category mentioned in section 45(1)(a), it would be unduly burdensome to arrange general practitioner medical and surgical services for themselves and their dependants, and*
 - (c) dependants who are ordinarily resident in the State of the persons referred to in paragraph (b).*
- (2) In deciding whether or not a person comes within the category mentioned in subsection (1) (b), the Health Service Executive shall have regard to the person's overall financial situation (including the means of the spouse²⁶, if any, of that person in addition to the person's own means) in view of the person's reasonable expenditure in relation to himself or herself and his or her dependants, if any.*

²⁶ The Revenue Commissioners are of the view [related to Data Protection] that it cannot, under the current legislative arrangements, supply Revenue information to the HSE in relation to spouses.

Medical Card application process

- 3.8 An individual may be entitled to a Medical Card if they are ordinarily resident in Ireland. Entitlement is decided by the Health Service Executive (HSE) and is mainly based on legislation as described above.
- 3.9 If an individual does not qualify for a Medical Card, then they may qualify for a GP Visit Card. This is also based on legislation, as described above.
- 3.10 The majority of Medical Cards are awarded on the basis of a means test together with an examination of an individual's medical and social circumstances. Every new application can go through four steps to determine their eligibility for a Medical Card or GP Visit Card.
- 3.10.1 **Step 1:** If an individual's assessed income is less than the income guideline ceiling, then they qualify for a Medical Card.
- 3.10.2 **Step 2:** If an individual's income is above the relevant guideline, then their medical and social circumstances can be taken into account to establish whether *undue hardship* would occur if they did not get a card.
- 3.10.3 **Step 3:** If an individual does not qualify for a Medical Card, they are then automatically assessed for a GP Visit Card. The income guideline ceilings are approximately 50% higher than those for a 'regular' Medical Card. If an individual's assessed income is less than the guideline, then they qualify for a GP Visit Card.
- 3.10.4 **Step 4:** If an individual's income is above the guidelines for a GP Visit Card, then again the medical and social circumstances are taken into account to see if it would be *unduly burdensome* for that individual to have to meet the GP costs themselves.
- 3.11 Current legislation requires that both an individual's income and expenditure (i.e. their overall financial situation) must be taken into account during the assessment process. 'Undue hardship' and 'unduly burdensome' do not appear to have significantly different meanings in the assessment process. For people aged over 70, applications are assessed on gross income at higher thresholds and expenditure is not taken into account. However, these individuals have the option of applying under the general Medical Card scheme, where the thresholds set are lower, and expenditure is taken into account in this process.

- 3.11.1 The assessment process²⁷ examines the individual's ability to meet the essential costs associated with maintenance of employment; provision of reasonable housing; provision of appropriate nurturing and care for children or dependants; provision of adequate heating, nutrition and clothing; coping with exceptional personal and financial burdens arising from medical or social circumstances.
- 3.11.2 Factors that are accounted for during this process include the illness or medical circumstances that result in financial hardship; the cost to the individual of providing general medical and surgical services; medical, nursing and dental treatment; physiotherapy; speech and language therapy; transport to hospitals and clinics; medical aids and appliances; social medical circumstances (e.g. addictions such as drink, drugs and gambling) and poor money management and social deprivation, including poor home management.
- 3.11.3 With the individual's consent the assessment process can also include advice from a wide variety of sources including the applicant. In making the decision the PCRS staff member does, in general, with the consent of the individual, liaise with the applicant's doctors, allied health professionals and others.¹
- 3.12 Medical Cards (or GP Visit Cards) awarded after an assessment of undue hardship or undue burden have become associated with the phrase 'discretionary Medical Cards'. The definition of discretionary is misunderstood and undoubtedly a cause of confusion. There is no difference between Medical Cards (or GP Visit cards) awarded purely on the basis of income being below the guidelines and Medical Cards (or GP Visit Cards) awarded after an assessment of undue hardship or undue burden.
- 3.13 Discretion is not a stand-alone exercise open to some and not to others; rather, it is an integral part of the assessment process for a Medical Card application.

Medical Card – Amendments by GPs

- 3.14 In February 2012, the HSE entered an agreement with the Irish Medical Organisation (IMO) whereby GPs, in certain circumstances, can make amendments to the Medical Card database by temporarily extending card eligibility for four months, or by restoring eligibility to a patient

²⁷ HSE Medical Card/GP Visit Card National Assessment Guidelines (January 2014)

who has had their eligibility removed due to not responding to renewal notices from the HSE.²⁸

- 3.15 In most cases where a GP amends the Medical Card database, third party verification is then sought from the family or a nursing home, or the HSE initiates a review of eligibility.
- 3.16 In 2012, GPs reinstated eligibility in 800 cases where they were of the opinion that eligibility had been removed in circumstances where the applicant had not responded to renewal notices, and eligibility should be restored.
- 3.17 The database was amended in 200 cases where GPs were of the opinion that it was a sensitive case. In such cases, eligibility is extended for a year. No third party verification is completed routinely, since by definition the purpose of this action is to prevent correspondence being issued to individuals not in a position to deal with such administration.

Emergency Medical Cards

- 3.18 An emergency Medical Card, valid for six months, can be issued within 24 hours of a doctor's report being made available in a number of circumstances, including for any patient who is in palliative care and is terminally ill; a homeless person in need of urgent medical care; a person with a serious medical condition in need of urgent medical care; a foster child in need of urgent medical care; an asylum seeker with a serious medical condition in need of urgent medical care.
- 3.19 Where a GP or consultant certifies that there is a terminal illness and the applicant is nearing the end stage of life, the nature of the terminal illness is not a deciding factor in the issue of a Medical Card, and no assessment of means applies.

Others with Medical Card entitlements

3.20 *People aged 70 years and over*

The Medical Card Scheme for people aged 70 years and over was revised with effect from 1 January 2014, resulting in changes to the qualifying gross income thresholds for Medical Card eligibility.

²⁸ Comptroller and Auditor General's *Report on the accounts of the public services 2012* (published September 2013)

3.21 *Thalidomide and symphysiotomy*

Any individual affected by the drug Thalidomide, or survivors of symphysiotomy, are entitled to a Medical Card, regardless of means. This arrangement is not on a statutory basis.

3.22 *Retention of Medical Cards*

At present, if an individual has a Medical Card and they take up employment or participate in a back-to-work scheme, then they may retain the Medical Card (for themselves and their dependants) for three years after their change of circumstances, even in the event that they do not continue to meet the means test or undue hardship requirements. This arrangement is not on a statutory basis. It was announced in Budget 2014 that this system would be changed via legislation to provide for an arrangement whereby such an individual would be given a GP Visit Card instead of a Medical Card.

3.23 *Hepatitis C/HIV*

Any patient who contracted Hepatitis C or HIV from the use of human immunoglobulin-anti D blood products is entitled to the same services as a Medical Card holder, and is also entitled to other services including home nursing, home help, physiotherapy, counselling services and such other services as may be prescribed by the Minister for Health. This is provided for under separate legislation – the *Health (Amendment) Act 1996* whereby the individual is entitled to a Health (Amendment) Act Card rather than a standard Medical Card.

3.24 *EU regulations*

Under EU Regulation 1408/71 each EU Member State is responsible for its own social security system and health service provision, and makes its own decision on the levels of social security and healthcare benefits it offers. The broad principle of the Regulations is that, if an individual moves from one country to another, then they are entitled to avail of health services in their new country on the same basis as if they were living in their home country. In practice, this means that people who are ordinarily resident in Ireland and who are covered by the EU Regulations are entitled to Medical Cards in Ireland.

Medical Card Benefits

Medical benefits

3.25 The main services to which Medical Card holders are entitled free of charge include:

- GP/family doctor services
- Approved prescribed drugs and medicines (subject to prescription charges)
- In-patient and day-case treatment in public beds in public hospitals
- Out-patient services in public hospitals
- Medical and midwifery care for mothers and infants
- A maternity cash grant for each child born
- Dental, ophthalmic and aural services.

3.26 While Medical Card holders are entitled to get approved prescribed drugs and medicines free of charge, they do nonetheless have to pay a prescription charge, which is currently €2.50 for each item dispensed, subject to a maximum of €25 a month for an individual or a family.

3.27 A GP Visit Card entitles the holder to GP/family doctor services free of charge.

Non-medical benefits

3.28 Medical Card holders whose income is more than €10,036 pay the Universal Social Charge (USC) but at a maximum rate of 4%.

3.29 The FOI application fee for a Medical Card holder in relation to non-personal information is €10 (standard fee is €15).

3.30 Medical Card holders are eligible for reduced charges for appeals under the Access to Information on the Environment (AIE) regulations.

3.31 Medical Card holder is an eligibility criterion for Higher Education Access Route (HEAR), a college and university admissions scheme that offers places on reduced points and extra college support to school leavers from socio-economically disadvantaged backgrounds.

3.32 Medical Card holders may also be exempt from paying school transport charges in publicly funded second-level schools.

3.33 Medical Card holders may also be exempt from paying State exam fees in publicly funded second-level schools.

3.34 Medical Card holders can avail of childcare at reduced rates under the Community Childcare Subvention Scheme.

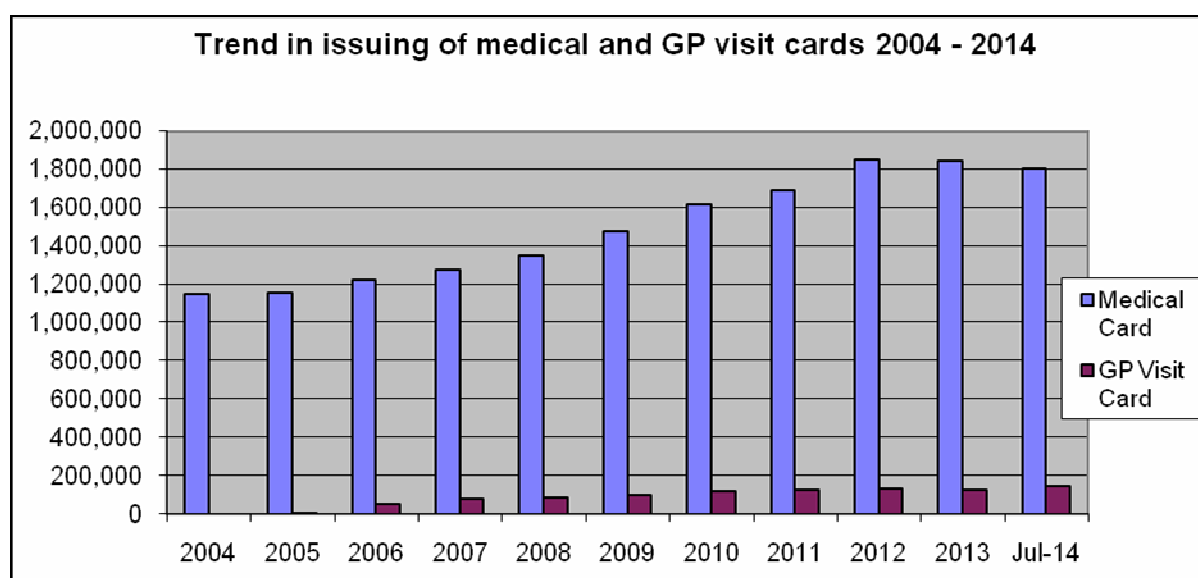
Medical Card statistics

3.35 Table 2 presents the numbers of full Medical Cards issued by year since 2004 and the numbers of GP Visit Cards issued since 2005. At the end of July 2014, over 1.8 million Medical Cards were issued, with a further 142,000 GP Visit Cards issued. Figure 4 illustrates the general trend regarding the issuing of Medical Cards and GP Visit Cards since 2004.²⁹

Table 2 Numbers of Medical Cards and GP Visit Cards issued 2004-July 2014

Year	Medical Card	% population covered	GP Visit Card	% population covered	Total
2004	1,148,914	29.3%	N/A	N/A	1,148,914
2005	1,155,727	29.5%	5,079	0.13%	1,160,806
2006	1,221,695	28.8%	51,760	1.22%	1,273,455
2007	1,276,128	30.1%	75,589	1.78%	1,351,717
2008	1,352,120	31.9%	85,546	2.02%	1,437,666
2009	1,478,560	34.9%	98,325	2.32%	1,576,885
2010	1,615,809	38.1%	117,423	2.77%	1,733,232
2011	1,694,063	36.9%	125,657	2.74%	1,819,720
2012	1,853,877	40.4%	131,102	2.86%	1,984,979
2013	1,849,380	40.3%	125,426	2.73%	1,974,806
July '14	1,804,376	39.3%	142,668	3.11%	1,947,044

Figure 4 Trend in the issuing of Medical Cards and GP Visit Cards



²⁹ Personal communication (A. Smith) 26 August 2014. Office of the National Director of Primary Care, Health Service Executive

3.36 Figure 5 and Figure 6 illustrates the distribution of medical cards by age group comparing 2006 versus 2013.

Figure 5

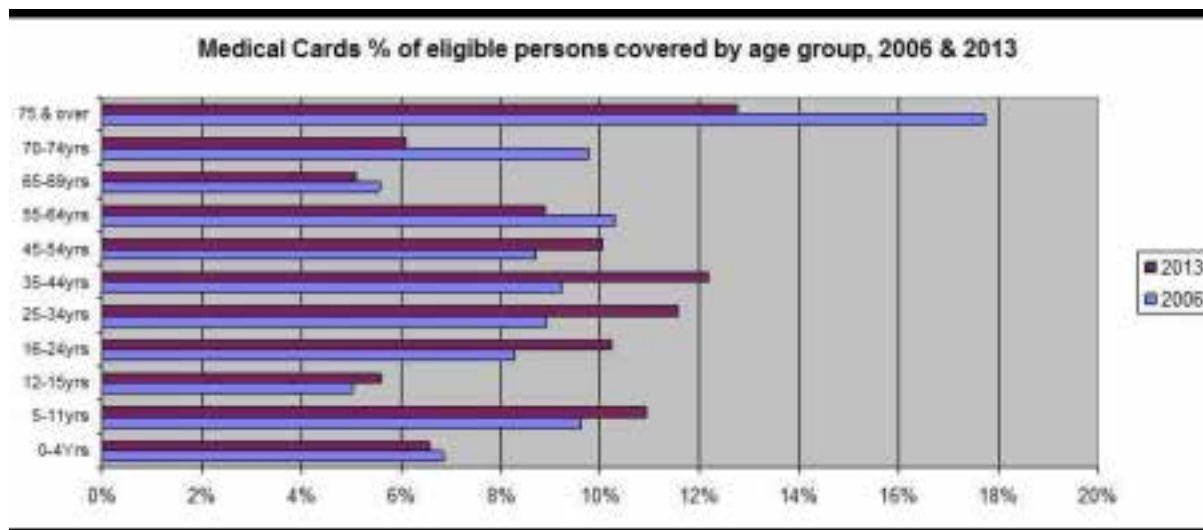
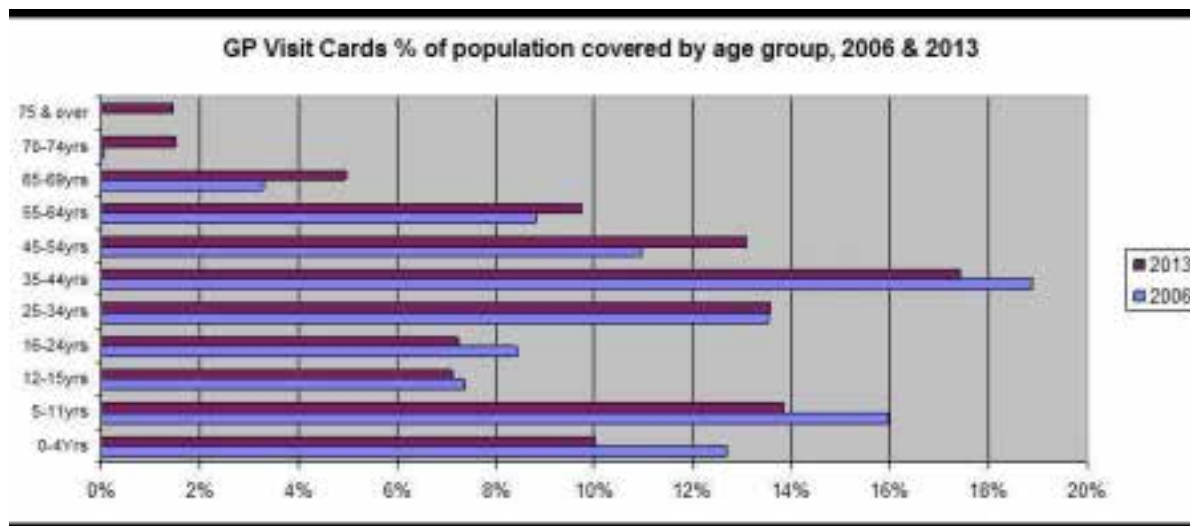


Figure 6



3.37 The data tables and figures reveal that:

3.37.1 There are over 1.9 million Medical Cards and GP Visit Cards in circulation in Ireland as of July 2014. This equates to 42.4% of the population.

3.37.2 Population coverage with Medical Cards (full eligibility) has increased steadily from 29.3% in 2004 to just under 40% as of July 2014.

3.37.3 The number of Medical Cards (full eligibility) in circulation in Ireland has increased by over 57% in the period 2004 to August 2014.

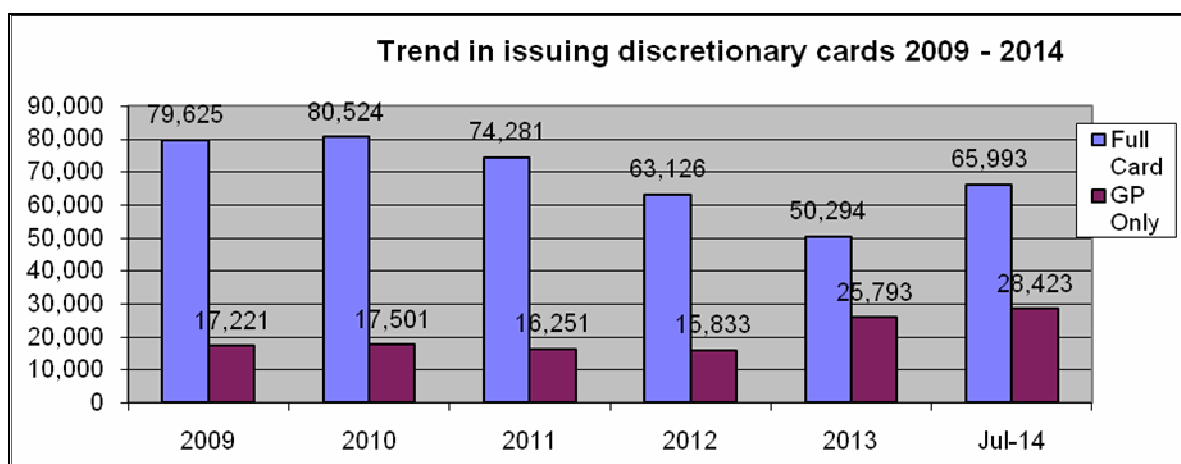
3.37.4 In the 65-69 years age category, 52.4% of people have Medical Cards or GP Visit Cards; 81.8% of those in the 70-74 age category have a Medical Card or GP Visit Card and 99.2% of those aged over 75 years have a Medical Card or GP Visit Card.

3.38 Statistics on the number of discretionary Medical Cards are only available since 2009. Table 3 summarises the numbers of discretionary Medical Cards in circulation for the period 2009 to July 2014, while displays the general trend over the same time period.

Table 3 Number and percentage of discretionary Medical Cards

Year	Medical Card	Discretionary	%	GP Visit	Discretionary	%	Total
2009	1,478,560	79,625	5.4%	98,325	17,221	17.5%	1,576,885
2010	1,615,809	80,524	5.0%	117,423	17,501	14.9%	1,733,232
2011	1,694,063	74,281	4.4%	125,657	16,251	12.9%	1,819,720
2012	1,853,877	63,126	3.4%	131,102	15,833	12.1%	1,984,979
2013	1,849,380	50,294	2.7%	125,426	25,793	12.1%	1,974,806
Jul-14	1,804,376	65,993	3.7%	142,668	28,423	12.1%	1,947,044

Figure 7 Trend in the issuing of discretionary Medical Cards



3.39 There are a number of points worth noting:

3.39.1 The number of discretionary Medical Cards has steadily declined since 2010, but against a background of an increase in the numbers of 'regular' Medical Cards.

3.39.2 The notable increase in the numbers of discretionary Medical Cards in the period end of 2013 to July 2014 is accounted for by the Government's recent decision to reinstate cards that had been removed in the period 1 July 2011 to 31 May 2014.

3.39.3 The number of discretionary GP Visit Cards showed a small decline in the period 2009-2012, but since then has seen a noticeable increase.

Medical Card costs

Comptroller and Auditor General – eligibility for Medical Cards

3.40 The Comptroller and Auditor General's *Report on the accounts of the public services 2012* (published September 2013) included an analysis of the administration and costs of Medical Cards.

3.41 The main components of Medical Card costs are payments to GPs and payments to pharmacists. Payments to GPs are categorised as fees and/or allowances. Fees are payable in relation to individual Medical Card patients registered on a per capita basis. GPs are also entitled to claim out-of-hours payments (where patients are seen outside normal practice hours) or where special services (excisions, suturing, vaccinations, catheterisation, family planning etc.) are delivered.

3.42 Drugs and medicines approved under the General Medical Service (GMS) Scheme are provided through retail pharmacies, and appliances are provided through Local Health Offices. The pharmacist claims the cost of the medicine provided together with a dispensing fee. The costs of the medicine provided comprise about three quarters of the total amount paid to pharmacists.

3.43 In 2002, the HSE paid a total of €823 million to GPs and pharmacists in respect of services provided to Medical Card users. By 2012, this had increased to just over €1.7 billion. Since 2005, total payments to GPs have ranged from €400 million to €450 million. In contrast, payments to pharmacists increased from €551 million in 2002 to €1.3 billion in 2012.

- 3.44 The average cost peaked in 2008, when the HSE paid service providers an average of €1,285 in respect of individuals in possession of a Medical Card. This had fallen to just over €1,000 per person in 2012.
- 3.45 The Comptroller and Auditor General made a number of comments and recommendations to the HSE in relation to the operation of the Medical Card system.
- 3.45.1 To conduct more internal reviews of Medical Card approvals, in order to ensure that prescribed controls are being applied. As part of this [C&AG] examination, the application of controls for the approval of Medical Cards was examined in relation to a sample of 50 Medical Cards approved during 2012. The review identified shortcomings in relation to 8% of the sample examined. Some of the shortcomings resulted in the approval of Medical Card applications in circumstances where the evidence would suggest that the applicant had not satisfied the eligibility criteria. In other cases, where outgoings had been assessed, the applicant supplied no documentation or inadequate documentation.
- 3.45.2 The available evidence suggests that there is a significant level of excess payment in the Medical Card system. In the main, this arises as a result of changes in the card holder's circumstances over the validity period of the card. The HSE should conduct reviews of random samples of Medical Card holders on an annual basis.
- 3.45.3 In order to calculate a reliable estimate of the level of ineligible card holding and the relevant costs, it is important that all cases for inclusion in the process should be selected randomly from the population of Medical Card holders at a specific time; the sample size should be sufficiently large to yield reasonably reliable estimates; the reviews should be carried out promptly following sample selection; a full review of eligibility should be conducted; and an assessment of the cost associated with ineligibility should be calculated with all results capable of being audited.

Other Primary Care Schemes and State supports

Drugs Payment Scheme

- 3.46 Under the Drugs Payment Scheme no individual or family in Ireland will pay more than €144 each calendar month for approved prescribed drugs, medicines and certain appliances for use by that person or his or her family in that month.
- 3.47 The definition of a family for this scheme is an adult, their spouse, and any children aged under 18 years. Dependants over 18 years and under 23 years who are in full-time education may also be included.
- 3.48 The Scheme is aimed at those who do not have a Medical Card and normally have to pay the full cost of their medication. It also applies to those who have a GP Visit Card. Anyone ordinarily resident in Ireland can apply to join the Scheme, regardless of family, financial circumstances or nationality.

Long Term Illness Scheme

- 3.49 People with certain long-term illnesses or disabilities can register under the Long Term Illness Scheme. This scheme allows a patient to get drugs, medicines, medical and surgical appliances directly related to the treatment of their illness free of charge. It does not depend on an individual's income or other circumstances, and is separate from the Medical Card and the GP Visit Card. A patient qualifies if they are ordinarily resident in Ireland, hold a Personal Public Service Number (PPSN) and have one of the following illnesses and disabilities:

- Acute leukaemia
- Mental handicap
- Cerebral palsy
- Mental illness (in a person under 16)
- Cystic fibrosis
- Multiple sclerosis
- Diabetes insipidus
- Muscular dystrophies
- Diabetes mellitus
- Parkinsonism
- Epilepsy
- Phenylketonuria
- Haemophilia
- Spina bifida
- Hydrocephalus
- Conditions arising from the use of Thalidomide.

Dental/ophthalmic and aural services

- 3.50 The Dental Treatment Services Scheme (DTSS) provides access to dental treatment for adult Medical Card holders (over 16 years of age). A free oral examination every calendar year and free emergency dental treatment for relief of pain and sepsis are available to all eligible patients. This includes two fillings per annum and all extractions.
- 3.51 Most other treatments require prior approval, and patients with special needs, as well as high-risk patients and those who have greater clinical needs, receive priority. The DTSS provides treatment for periodontal/gum disease in cases where care is especially warranted. This includes clients who are pregnant, have diabetes or immune-compromising conditions, or require relevant surgical procedures such as cardiac surgery and joint replacements. Approval for periodontal treatment may be given by the local Principal Dental Surgeon for these and other high-risk or special needs groups.

High Tech Drug Scheme

- 3.52 Arrangements are in place for the supply and dispensing of high-tech medicines through community pharmacies. High-tech medicines are, typically, expensive medicines that have been produced by biotechnological means, or contain new drugs with significant new therapeutic uses, or require prescribing by a consultant in a hospital setting.
- 3.53 High-tech medicines are generally only prescribed or initiated in hospital, and typical examples would include drugs to prevent transplant organ rejection, as well as some cancer treatments and assisted reproductive technology medicines. The medicines are purchased by the HSE and are supplied through community pharmacies, and pharmacists are paid a patient care fee. The cost of the medicines and patient care fees are paid by the PCRS.
- 3.54 If an individual has a full Medical Card, or if the medicine is being used to treat one of the illnesses specified under the Long Term Illness Scheme, then there is no charge for their high-tech medicine. Patients with eligibility under the Health Amendment Act are also exempt from a charge. All other patients are required to pay the monthly Drugs Payment Scheme (DPS) contribution (currently €144).

Community Ophthalmic Services Scheme

3.55 Under the Health Service Executive Community Ophthalmic Services Scheme, adult Medical Card holders and their dependants are entitled, free of charge, to eye examinations and necessary spectacles/appliances. Claims by optometrists/ophthalmologists are paid by the PCRS. Claims for spectacles provided under the Children's Scheme are also paid by the PCRS.

Tax relief and medical expenses

3.56 Any individual who incurs medical expenses that are not covered by the State or by private health insurance may claim tax relief on some of those expenses. These expenses include the costs involved in nursing home care. However, it is not possible to claim tax relief for any expenditure which has been, or will be, reimbursed by another body, such as the VHI, Laya Healthcare, Hibernian Aviva Health, the Health Service Executive or other body or person; has been, or will be, the subject of a compensation payment; or relates to routine dental and ophthalmic care.³⁰

- Costs of doctors' fees and consultants' fees
- Items or treatments prescribed by a doctor or consultant
- Maintenance or treatment in a hospital or an approved nursing home
- Costs of speech and language therapy carried out by a speech and language therapist for a qualifying child
- Transport by ambulance
- Costs of educational psychological assessments carried out by an educational psychologist for a qualifying child
- Certain items of expenditure in respect of a child suffering from a life-threatening illness
- Kidney patients' expenses
- Specialised dental treatment
- Routine maternity care
- In-vitro fertilisation.

The following, where prescribed by a doctor, also qualify for medical expenses relief:

- Drugs and medicines
- Diagnostic procedures
- Medical, surgical, dental or nursing appliances
- Hearing aids
- Orthopaedic bed or chair

³⁰ <http://www.revenue.ie/en/tax/it/leaflets/it6.html>

- Wheelchair or wheelchair lift (no relief is due for alteration to the building to facilitate a lift)
- Glucometer machine for a diabetic
- Engaging a qualified nurse in the case of a serious illness
- Physiotherapy, chiropody/podiatry services or similar treatment
- Cost of a computer where there is medical evidence that it is necessary to help a person with a severe disability to communicate
- Cost of gluten-free food for coeliacs. As this condition is generally ongoing, a letter (instead of prescription) from a doctor stating that the individual is a coeliac sufferer is acceptable.

3.57 Tax relief is also available for premiums paid for health insurance. Tax relief on private health insurance premiums is limited to €1,000 for each adult and €500 for each child.

4. THE VOICE OF THE PUBLIC, THE PATIENT AND REPRESENTATIVE PANELS

Introduction

4.1 In order to assess the public's opinion as to whether or not medical needs should be taken into account in the provision of Medical Cards, a public consultation process has been carried out by the HSE in order to inform the development of a new policy framework for Medical Card eligibility. There have been two independent component parts of the public consultation processes.

On-line public consultation exercise

4.2 In June 2014 the Primary Care Division of the HSE invited submissions using an on-line form. The survey was launched on 6 June 2014 and submissions closed on 30 June 2014. A total of 3,248 responses were received and analysed by the Division of Population Health Sciences, Royal College of Surgeons in Ireland.

4.3 There were 20 written submissions by disease association/patient advocacy groups to the Expert Panel; these submissions were too large to be qualitatively analysed by the online process and were separately analysed by Dr Marie Eagleton, HSE Medical Scientist (this report is titled *Patient Association and Patient Advocacy Group Submissions*).

The Patient Representative Forum on Medical Card Eligibility

4.4 The Patient Representative Forum on Medical Card Eligibility was hosted by the HSE National Advocacy Unit and was held in the Ashling Hotel, Dublin on 26 August 2014.

A summary and the results of each of these exercises are presented below.

On-line public consultation

4.5 In May 2014, the Primary Care Division of the HSE established an on-line public consultation for submissions to inform the development of a new government policy framework for Medical Card eligibility. Submissions were requested from the public, patient representative groups and professional bodies, to inform the work of the Expert Panel in examining the range of medical conditions that should be considered for inclusion in this new policy framework. The Public Consultation entitled '*Have your say on the medical needs that should be taken into account in the provision of Medical Cards*' invited submissions to be made using an online form or via email, audio or by post. The closing date for submissions was Monday, 30 June 2014. A total of 3,248 responses were received via the on-line form.

Methods

4.6 The survey asked respondents to provide contact information, such as name, group they were representing (if applicable), address, telephone number and email address. The remainder of the survey comprised 11 open-ended (free text) questions and 8 pre-coded questions. Respondents were asked to indicate if they were a person living with a condition, or if they were an individual or group connected in some other way. Detailed information on medical needs that arise based on these conditions was elicited by asking participants to provide the following information in free text comment boxes: medical condition(s); reasons why this condition should be considered on the basis of medical need; GP visits e.g. number, frequency of visits etc.; medicines e.g. range of medications required; therapies e.g. occupational therapy, physiotherapy and other therapy support needs and frequency; aids and appliances e.g. home support equipment and other medical devices; in-patient treatments, e.g., hospital-based care needs; respite care requirements; other. Participants were then asked to provide ratings (from 'Not at all' to 'Very much') of how much their condition typically effects their normal activity; physical function; mental health; social function; energy; pain; work. A final free text comment box prompted participants to include any further relevant information they wished to add. All records were anonymised before analysis was undertaken.

Analysis

4.7 This report presents analysis of the 3,248 on-line submissions. Descriptive statistics of responses are presented, where quantitative summation was possible. Free text responses were analysed qualitatively. Qualitative analysis involved assigning categories based on the criteria of repetition, recurrence and forcefulness of various topics or themes in the responses to the open-ended questions. These categories were used to code the open-ended question in the analysis. The open-ended responses were further analysed to provide exemplars of a particular topic or theme and were used to highlight in this report the key issues raised.

Summary of key findings

4.8 The quantitative analysis indicated high health service utilisation among this group, with 40% visiting the GP between five and twelve times a year. A small minority (less than 2%) do not take any medication, while a third of respondents take five or more medications. Almost half of respondents indicated needs for hospital services; 50.5% of respondents and 30% of respondents indicated need for in-patient and out-patient services, respectively. Other therapy (including alternative and complementary therapies) as well as technical aids and appliances are also an area of great need for people. Just over half mentioned the need for physiotherapy and almost 12% mentioned needing some form of complementary therapy;

42.5% mentioned use or need of multiple aids and appliances. These findings combine to highlight the broad range of services required to support individuals and their families not only to live a life with chronic illness, but to live a life that is full, complete and inclusive, providing equitable opportunity and choice in all aspects of life. Qualitative analysis of the free text responses provides insight into the challenges faced by people in accessing the appropriate services at the appropriate time. Poor health and unmet health needs were reported as having a domino effect on all other aspects of an individual's life, ultimately impacting on society as a whole.

Financial impact

4.9 Respondents alluded to difficult decisions being made between accessing GP services for their children or another family member to the detriment of their own health; foregoing necessary GP and/or hospital visits due to cost. A recurring theme also was restricting medication use, again due to cost. Going abroad to source cheaper medications or specialist care not available in Ireland was a strategy followed by some. Sourcing medication or specialist care in this way added to the financial burden for those with the health condition and their families, and also created logistical, travel and emotional stress for the individual and their family.

Emotional impact

4.10 The sense of worry, anxiety and stress associated with access (or not being able to access) appropriate health care, and financial concerns associated with cost of care and medications were prominent throughout the submissions.

Family impact

4.11 The impact on family was also clear. Respondents noted how other children within the family may not receive equal attention, or how families may not be able to take holidays due to providing care and the cost of care of one sibling. Stress and strain in caring for family members was reported in addition to the huge responsibility placed on families to administer medical/therapeutic care at home.

Impact on work/schooling

4.12 The individual is often faced with the decision to work (and lose the much-needed Medical Card) or to keep the card but not work. The submissions indicate the negative impact that not working or missing work due to illness can have on the individual's sense of self, quality of life, and ability to contribute in a meaningful way both economically and socially. Education is also

impacted through reduced attendance at school, due to illness or hospital/clinic appointments. Participation in school life is affected by access to appropriate supportive aids, and also the extent to which recreational/sporting activities can be inclusive of all children. In many cases, children with chronic illness are excluded from such activities and it is the family who supplement these activities outside school hours.

Conclusion

4.13 Overall, the findings of the online public consultation survey highlight that having a chronic illness is not about diagnosis alone. Respondents in the consultation indicated that the overriding challenge for individuals and families alike is accessing the required health services while also balancing all other aspects of life (work, family, mental health). In particular, the challenge most prominently reported is the ongoing difficulty of trying to balance the individual and/or family budget to enable access to care for all as needed. As one participant surmised:

“It’s hard enough trying to cope with a chronic illness without the expense and stress making my future look so bleak.”

Patient association and patient advocacy group submissions³¹

4.14 There were twenty submissions by disease association/patient advocacy groups to the Expert Panel on Medical Card Eligibility, and there were six individual submissions. The twenty group submissions are listed below. All diseases and conditions were chronic, lifelong or had a relapsing-remitting course. The submissions varied in the level of detail supplied, but a number of common themes emerged.

4.14.1 Respondents strongly urged that allocation of Medical Cards should be based on medical need rather than having a medical condition. The prevalence of a condition should not be a basis for entitlement to a Medical Card, and respondents do not want to see a situation where there would be competition between conditions for Medical Cards. An objective assessment of medical need would avoid this; Medical Cards should be about medical need, and personal financial circumstances should not be taken into account when assessing for a discretionary Medical Card.

³¹ Twenty written detailed submissions were received by disease association/patient advocacy groups and a further six were submitted by individuals.

- 4.14.2 It was acknowledged that medical need could be transient in nature and that a mechanism for rapid assessment of medical need would be developed. This would facilitate issue of Medical Cards when they were needed, and withdrawal of these cards if and when the disease was in remission.
- 4.14.3 It was noted that accessing community-based services without a Medical Card is difficult, and that paying for necessary aids and appliances is financially burdensome. The following is a quote from the Irish Cancer Society Submission:
- “...patients who do not have a Medical Card face significant costs to care for themselves at home. What is particularly stark is that without a Medical Card they do not have guaranteed access to a public health nurse or allied community-based professionals.”*
- 4.14.4 Many of the respondents indicated that the current system for allocation of medical cards did not discern the true cost of chronic illness. Some submissions provided information on the cost of these illnesses to patients and their families, which significantly reduces their disposable income. The prospect of withdrawal of discretionary Medical Cards by those who already have them provokes a lot of anxiety in families.
- 4.14.5 Many patients with chronic conditions who do not have Medical Cards pay up to the maximum for prescription drugs every month and visit GPs more frequently than normal, which causes undue financial hardship. Furthermore, in addition to paying the maximum for medication, some patients pay for essential supplements and drugs not covered by the Drugs Payment Scheme (DPS), and may often have to pay for other therapies: chronic disease incurs a lot of expense.
- 4.14.6 There are anecdotal reports that people with chronic conditions who do not have Medical Cards do not fully comply with medication, or attend the GP or hospital appointments with necessary regularity, for financial reasons.
- 4.14.7 The respondents indicated that many people with chronic illnesses who already have Medical Cards are uninclined to take up employment because they may lose their Medical Card on financial grounds. This further increases their dependency on the State and has a detrimental effect on their wellbeing.

4.14.8 It was noted by some respondents that having a Medical Card opens up other non-medical benefits such as free school bus service, and decoupling of these services was urged.

4.14.9 Many of the submissions commented on the administration of Medical Cards and how difficult it is for the individual to navigate the system, which is seen as overly bureaucratic, inaccessible and insensitive in its approach to ill people.

PATIENT GROUP	CONDITION	INCIDENCE (IRELAND)	SYSTEM AFFECTED	DRUGS	SERVICES REQUIRED	OTHER
Lupus Group Ireland	Lupus conditions e.g. SLE autoimmune	4,000 Highest F (15-40 years)	Multisystem	Immunosuppress Antibiotics etc.	Hospital Multiple GP visits, physiotherapy Counselling Sunblock	
Alternating Hemiplegia of Childhood Ireland (ahci)	Alternating hemiplegia of childhood; probably genetic	8 most < 12 years	Neurological	Antiepileptic drugs (AED)	Regular GP, hospital, physiotherapy, occupational therapy; aids and appliances	High childcare costs
Prader-Willi Syndrome Association Ireland (PWSAI)	Prader-Willi syndrome Genetic	100	Endocrine, developmental skeletal system motor function	Endocrine thyroid Rx	Multiple GP visits, physiotherapy, speech and language, dietetics, aids and appliances	Food security
Myalgic encephalomyelitis/Chronic Fatigue Syndrome Association (ME/CFS)	Chronic fatigue Cause not fully understood	10-12,000 Mostly females	Multisystem	Sleeping Pain relief	GP; physiotherapy; occupational therapy; Aids and appliances Counselling	
Williams Syndrome Association of Ireland	Williams syndrome Genetic	200 (approx.) < all 50 years old	Multi-organ, cardiovascular orthopaedic and intellectual		Medical dental, physiotherapy, psychology; psychiatric	Corrective surgery; cardiac; orthopaedic
Cleft Lip and Palate Association of Ireland (CLAPAI)	Cleft Genetic	650 approximately (1 in 700 births)	Head and neck		Hospital; surgical, dental speech therapy; occupational therapy; psychology therapy	Corrective and plastic surgery Orthodontist
Lymphoedema Ireland	Lymphoedema Frequently secondary to cancer treatment	15,000	Lymphatic system		Occupational therapy; physiotherapy; massage therapy Compression garments and garmenting aids	High social service need
Irish Society for Colitis and Crohn's Disease (ISCC)	Inflammatory bowel disease autoimmune	20,000 Most 15 to 35 years second peak 60-79 years	Gastro-intestinal tract	Immunosuppress therapy;	GP. Hospital drugs and supplements not covered by DPS. Aids (e.g. stoma) Counselling	Specialised expensive dietary requirement. Additional tuition due to missed schooling in children
Epilepsy Ireland	Epilepsy	36,844 > 5 years	Neurological	AEDs	GP; hospital due to injury; calcium supplements not covered by DPS	Behavioural therapy in children, orthopaedic and dental treatment as a result of injury
Post-Polio Support Group	Polio survivors	7,000 Most aged 40 to 80 years	Neurological muscular	Pain	GP neurology, physiotherapy, occupational therapy, speech and language therapy, podiatry/chiroprody/dietetics, pain specialists, social workers respiratory medicine, orthotics	
Move4Parkinsons	Parkinson's disease	8,000 approximately Most > 50years	Neurological	Wide variety of drugs	Physiotherapy, occupational therapy, speech and language therapy, dietetic services and psychotherapy	
Addison's Ireland	Addison's disease	500 to 800 All ages	Adrenal endocrine	Steroid	GP, hospital, physiotherapy	
Irish Heart Foundation	Cardiovascular disease	30,000 stroke survivors	Cardiac Vascular system	Wide variety		

PATIENT GROUP	CONDITION	INCIDENCE (IRELAND)	SYSTEM AFFECTED	DRUGS	SERVICES REQUIRED	OTHER
Arthritis Ireland	Arthritis	1 million	Joints, skeletal system, immune system	Anti-inflammatory pain relief, disease modifying drugs	Physiotherapy, occupational therapy	Aids and appliances, community supports
Irish Cancer Society	Cancer	34,000 per annum	Multi-organ	Wide variety of drugs	Wide range of services	Community support
Irish Hospice Foundation	Palliative care	No numbers given	n/a		Palliative care	
The Little People of Ireland	Dwarfism	70 approximately	Skeletal, muscular	Pain inflammation,	Surgery, occupational therapy, podiatry community services	
Disability Federation of Ireland	Umbrella organisation					
Rehab Group	Umbrella organisation					
Neurological Alliance of Ireland	Umbrella organisation					

The Patient Representative Forum on Medical Card Eligibility

Introduction

- 4.15 The Patient Representative Forum on Medical Card Eligibility was held on 26 August 2014 in the Ashling Hotel, Dublin. This forum was part of the consultative process that will inform the work of the Expert Panel appointed by the HSE to examine a range of issues around Medical Card eligibility. The consultative process included feedback received through the on-line Public Consultation Feedback Form and written submissions made by a number of patient representative organisations.
- 4.16 The forum was chaired by Greg Price, Director of Advocacy. It was addressed by John Hennessy, National Director of Primary Care, who spoke about the review of the eligibility for Medical Cards which was undertaken by the Expert Panel and incorporated a public consultation process. A total of 3,248 submissions were received as part of this process and were analysed by the Royal College of Surgeons in Ireland. A separate review of the administrative process of Medical Card assessment was undertaken by Deloitte and Prospectus. Reports from both review groups are expected by the end of September 2014.
- 4.17 The purpose of the Patient Representative Forum was to inform the work of the Expert Panel and to focus on the qualitative aspect of public consultation by capturing the views of patient representative groups. Key themes from the forum were captured in a report and submitted to the Expert Panel.
- 4.18 The forum was attended by representatives from 24 patient representative groups and was facilitated by the HSE Advocacy Unit. Two discussion sessions took place, with each comprising the following series of questions:

Discussion 1

1. How can society **fairly measure** the burden and impact of a disease or condition on an individual?
2. How can society **compare** the burden and impact of different diseases/conditions i.e. a patient with condition X versus a patient with condition Y? For example, a patient with diabetes versus a patient with cancer.

Discussion 2

Irrespective of the recommendations of the Expert Panel, if you could do three things to change how the current system is operated what would they be? Patient representative groups were also asked to complete a questionnaire. Completed questionnaires will be submitted to the Expert Panel for use in their deliberations.

Key themes

The following common themes emerged in the discussion in all of the groups:

- 4.19 There is a need to move away from purely financial assessment and look at the quality of life of an individual, rather than just their disease or condition. What is it like for someone to live with a condition or participate in everyday tasks or functions? What impact is their condition having on their ability to participate in society/community? What impact is it having on their family, social life, carers, mental health and assistance needs? Quality of life was also described at a minimum as lack of pain, particularly for someone with a chronic or long-term illness. At the moment, expert decision-makers in the PCRS cannot see what the quality of life is like for a person with a chronic or lifelong illness.
- 4.20 Most of the groups felt that it was morally and ethically wrong to compare/pit one condition/disease against another. However, groups discussed the possibility of developing a measurement tool that could be used to measure the impact of a disease or condition on the quality of life of an individual.
- 4.21 Examples of existing tools that can be considered or adapted for Medical Card assessment were discussed. These examples are further explored in detail below as part of the feedback on each question.
- 4.22 Decoupling of the Medical Card from other areas of social benefits that are currently linked to Medical Card possession, such as school buses, exam fees, etc.
- 4.23 Redefining the Medical Card as a 'healthcare access card' to reflect varying levels of care required depending on the need and severity of a condition. Not one size fits all.

Discussion 1

*Question 1: How can society **fairly measure** the burden and impact of a disease or condition on an individual?*

- Develop fair, standardised measurement tools that are cognisant of:
 - Quality of life
 - Extent of reliance on medicines, medical equipment and medical intervention to sustain quality of life and offset deterioration or risk
 - Length of time spent in treatment, requirement for regular GP visits, outside care support
 - The cost of medication, where the cost of medication regularly exceeds the threshold of the DPS; requirement for equipment and appliances not covered by DPS
 - Pre-condition and post-condition; the impact the condition has had on a person if it was not a condition at birth
 - Functionality
 - Prognosis
 - What social supports are required
 - The impact of not providing care, i.e. long-term costs and effects on the life of the person.

- Need to look at the financial impact, physical impact, psychological impact, social impact, mental health impact; how an individual can carry out everyday normal activities; family and whether social/family supports are available or not.
 - For example, there are 1,000,000 people with arthritis, but not advocating that everyone with arthritis should get [a Medical Card]. Someone with arthritis may need paracetamol three times a day and they can function okay, but another patient with arthritis may need expensive prescriptions, physiotherapy, invasive treatments, frequent hospital stays. The impact or burden of disease is not the same.

- Need to look at co-morbidities as part of the assessment.

- Introduce a single assessment tool. Can look at some of the existing tools that may be adapted for Medical Card assessment. For example:
 - SATIS is used for assessments of older persons (Fair Deal). Assesses family/social supports, medical needs, and financial situation.
 - Patient reported outcome measures (PROMs)
 - Disease activity score

- MS patients have levels or scores that relate to the level of assistance they need e.g. how many people a person with MS may need in order to carry out an activity of living. The scoring is usually done by a physiotherapist, occupational therapist or nurse.
- Consultants already use assessment tools for different conditions/diseases. These can be looked at as part of the work of the Expert Panel.
- Is the condition lifelong and enduring? Certain lifelong, enduring conditions should get automatic entitlement to Medical Cards. However, certain conditions can fluctuate. For example, someone with chronic lung disease who automatically has a Medical Card for up to three years could be well for the duration of this card, and the card could have been given to someone else who had a greater need during that period of time.
- Conditions with no cure should be prioritised.
- A database of conditions is needed or a National Register of Diseases.

*Question 2: How can society **compare** the burden and impact of different diseases/conditions i.e. a patient with condition X versus a patient with condition Y? For example, a patient with diabetes versus a patient with cancer.*

- Most of the groups expressed the view that we cannot compare these situations and is a hugely ethical and potentially divisive issue. Instead, we need to look at how someone can live with a disease and the consequent effects on their quality of life.
- The emphasis should be on comparing Health and social burden on an individual, not on comparing specific conditions.
- Cannot compare someone with diabetes to someone with cancer. Chronic versus acute condition.
- Cannot fairly compare conditions, and there should be individual reviews by people who are informed and aware of issues/conditions.
- The process should not be about placing one particular condition over another, but rather about establishing the appropriate level of eligibility for each.
- It is important to consider the negative costs of not providing care. For example, it is estimated that 60% of amputees have diabetes, so the question is could some amputations be avoided by early intervention for people with diabetes?
- Need to look at engaging patients with chronic conditions in a meaningful way, for example using adherence programmes and chronic disease self-management programmes. It is not good enough to hand someone a prescription. The cost of non-adherence can be high for the health system.
- Once a person has received a Medical Card, they should also take responsibility for looking after their own health.

Discussion 2

Irrespective of the recommendations of the Expert Panel, if you could do three things to change how the current system is operated, what would they be?

1. Review and restructure the system of resource allocation.
 - For example, look at creating patient co-ops, new models of social market.
 - Review the financial mechanisms of how the health service is structured, particularly at primary care level. GPs should only be paid for every clinical interaction with a Medical Card holder, instead of the current situation where GPs are given an annual allowance even if they never have reason to provide treatment to a Medical Card holder.
 - Money should be following the patient, instead of money being given to a service without any analysis of the benefits/drawbacks to that service.
 - Award full eligibility to an individual independently; take account of a child in their own right by way of processes and documentation. For example, all members of a household should not necessarily receive Medical Cards following an application from a single family member suffering with a serious condition.
2. Decouple the Medical Card from other non-health-related benefits, for example school buses and exam fees. A Medical Card should not be used as a gateway to other supports. Perhaps a different card could be introduced for these benefits, and could be administered by the Department of Social Protection? Examples were given of where young healthy adults on low incomes apply for a Medical Card in order to get access to other benefits, while parents who are slightly over the financial threshold and have a child with special needs do not get a Medical Card.
3. Medical Cards should be about medical needs. Granting eligibility on the basis of medical need should give rise to a new type of card, a 'Health Access Card'. Trust the medical professionals to assess the condition and determine Medical Card eligibility.
4. Redefine the Medical Card and introduce:
 - a. Medicines card
 - b. Health and social services card
 - c. Primary care card

Assess for all three cards, but the individual may only need one type. Assessment should be for a specific individual, not for the whole household.

5. Take the stress out of the application process. For example:
 - a. Get temporary access to care during the process. This can prevent exacerbation of a condition due to delay in receiving treatment, or due to stress.
 - b. Accessible information is needed in order to make the process transparent and easy to understand for all. Clarity is required with regard to entitlements.
 - c. Information on Medical Cards for terminally ill patients should be available – the emergency Medical Cards application process is not explained anywhere.
 - d. Ensure the involvement of social workers in assisting with applications for Medical Cards for sick children, or for babies requiring palliative care who are about to leave a hospital/maternity unit. Assistance is needed for parents who are already dealing with the stress of a serious diagnosis for their child.
 - e. Too great a burden of proof is placed on the applicant.
 - f. A person should not have to reapply every three years for a Medical Card if that person has a lifelong medical condition.

6. Improve the means testing system, making it simpler. The same system can be used by all Government Departments. Different means tests are being used by the Department of Social Protection, HSE, etc.

7. It was felt by one of the groups that the Expert Panel mainly comprised medical professionals and was not representative of wider society. The suggestion was made that the Expert Panel should be disbanded and a new expert panel formed to include an international expert, patient representative as well as representatives from the following:
 - Tax and social services
 - ESRI
 - PCRS
 - Department of Public Expenditure and Reform
 - Social justice, e.g. Society of Saint Vincent de Paul (SVP).

Concluding remarks

- 4.24 Overall, the discussion in all groups was very productive, and all participants actively engaged in the discussion. The feedback received from patient representative groups following the workshop was positive. They found the forum useful, and expressed an interest in participating in further discussions on Medical Card issues.
- 4.25 There was willingness to have an input into improving the way Medical Cards are allocated. While representatives of different patient groups were fully aware of the needs of the patients they were representing, the issues that were discussed and the suggestions that were made to improve the system took into account the bigger picture and needs of patients with different conditions. This was reflected in the feedback and the common themes in all the groups who took part in the discussion.
- 4.26 An undertaking was given that the report, incorporating feedback from group discussions, will be shared with the attendees.

5. EXPERT PANEL – APPROACH AND METHODOLOGY

Expert Panel Commentary on the Medical Card system

5.1 The Expert Panel, although tasked with attempting to list medical conditions as to their suitability for Medical Cards felt that it was also important to comment on the present Medical Card system because the two elements, Medical Cards and medical conditions, are potentially so inextricably intertwined.

The whole health system

5.2 The Medical Card and health benefit systems have evolved in a piecemeal manner over the years as a response to political/other initiatives and requirements, such that the whole has become complex, not logical, and therefore often difficult to understand for patients, administrators and health workers alike.

5.3 Two Departments (Health and Social Protection) are largely responsible for delivering health, illness and disability supports. In March 2013 legislation was passed which created the legal basis for the sharing of records between the PCRS, the Department of Social Protection (DSP) and the Revenue Commissioners. This is a welcome development, as it allows for further improvements in the management of the GMS Scheme, and offers an additional assurance that Medical Card eligibility can be provided to people appropriately and in line with current eligibility criteria. Even greater congruence in the future will be helped by the implementation of a Unique Patient Identifier (UPI) system.

The General Medical Service Scheme

5.4 The Medical Card and related cards have evolved as means-tested, 'hardship' cards that open up access to a range of public services. While the Medical Card's predominant offering is healthcare benefits, it also facilitates access to a range of financial, educational, transport and social service benefits amongst others.

5.5 The assessment and identification process of financial hardship i.e. means testing would not appear to be a natural best fit for the health service, but rather a function that would more appropriately sit in the Department of Finance or Department of Social Protection. It is from one of these Departments that other Departments, including Health, should access financial information.

- 5.6 The role of the health service would appear to be better placed to use third-party provided means-tested information, and then also to define and identify an additional layer of ‘medical hardship’ or ‘burden of disease’.
- 5.7 Currently, because of the considerable range of benefits offered by the Medical Card system, it is not surprising that the main motivation of some applicants in resisting the loss of a Medical Card is for predominantly non-medical reasons, such as school transport, rebates on childcare fees, exam fees etc.
- 5.8 When this Medical Card system was originally introduced there was an interpretation in some areas that it would be valid for life.³² Thus, it is not inconceivable that many people cancelled their private health insurance, and now find themselves in difficulty and unable to restore insurance cover.
- 5.9 While there is general understanding that the issuing of Medical Cards offers a range of services to individuals and families, this may be of no value unless those services are both accessible and adequate. If deficits in the current and predicted numbers of GPs are not corrected, then universal primary care ‘without barriers’ will not become a reality.
- 5.10 The provision of comprehensive GP and other primary care services would deliver the additional benefit of redirecting pressure away from acute hospital services. Our current system has the perverse incentive of directing patients who do not have a Medical Card (or GP Visit Card) to preferentially attend a hospital out-patients department because there is no fee for this service, as opposed to directing them to attend a GP’s surgery, where they would have to pay a fee.
- 5.11 There is clearly an unequal and therefore inequitable distribution of Medical Cards in addition to the services they offer throughout Ireland (Figure 1).

³² The Comptroller and Auditor General’s *Report on the accounts of the public services 2012* (page 239): “The HSE recognised that assessment for eligibility for medical cards was not consistent between the 100 [local health] offices conducting the reviews and some card holders were granted medical cards for long periods, in some cases up to 20 years.”

Primary Care Reimbursement Service (PCRS)

- 5.12 Currently, the Primary Care Reimbursement Service (PCRS) performs two functions. The first is the administration of the Medical Card and other Primary Care schemes, and the second is the reimbursement of contractors – two functions that might be better served if they were managed separately. A review of the role of the PCRS in the administration of the Medical Card system is currently being undertaken by Prospectus and Deloitte. The primary objective of their review is to examine how the PCRS administers the Medical Card application process and recommend ways in which the process could be made more efficient, simple and user-friendly, as well as identifying areas where communications could be improved.
- 5.13 Although the centralisation of administration of Medical Card eligibility assessment has allowed the introduction of a standardised system for assessment of eligibility, it has unearthed and revealed a certain level of non-renewal amongst Medical Card holders. In the context of discretionary Medical Cards, the significant upset and disquiet has undoubtedly been exacerbated by the level of variability in their award, prior to 2011, across the 26 counties that ranged from 3-12/100,000 population to 39-53/100,000 population.³³
- 5.14 Approximately 4,000 calls and queries are received by the PCRS per day. In addition, the weekly average for telephone contacts from Oireachtas Members was 564 calls (period: January to June 2014) and the weekly average for emails received was 615 (period: 5 May to 23rd June 2014). Since January 2014 over 825 Parliamentary Questions (PQs) were forwarded to the PCRS, approximately 25% of the total number of PQs directed to the HSE. This can only be interpreted as an indication of the level of dissatisfaction by the public and elected representatives with the administration of the current system. The number of calls and queries is a massive burden that is unsustainable and will remain a significant impediment to the efficient running of the PCRS until the structural and operational problems within the PCRS are rectified.

³³ Personal communication, July 2014. HSE, Office of National Director of Primary Care

Expert Panel exercise on medical conditions

5.15 In its Terms of Reference, the Expert Panel was tasked with advising on the appropriate approach to identify and examine medical conditions, the treatment and management of which would benefit most from access to services currently only available to persons with full Medical Card eligibility. At a more fundamental level this has been interpreted as asking the Expert Panel to list conditions in priority order as to their edibility to receive a medical card.

5.16 The Expert Panel was determined to be fully transparent in its approach, deliberations and the individual and collective difficulties posed. Each member of the panel was asked to undertake an exercise whereby they were challenged to prioritise a list of conditions³⁴ that in their professional opinion deserved a Medical Card, independent of means testing.

5.17 A number of 'levels' were proposed to assist the Expert Panel with the prioritisation exercise. As follows:

- Level 1 conditions were defined as those which, irrespective of their grade of severity, have a lifelong effect and, by implication, would be deserving of a Medical Card.
- Level 2 conditions were defined as those which, at more severe grades of severity that can clearly be defined, have a lifelong effect.
- Level 3 conditions were defined as those which, at more severe grades of severity that can clearly be defined, have a prolonged effect (one year or greater).
- Level 4 conditions were defined as those which, at more severe grades of severity that cannot clearly be defined, may have a lifelong effect.
- Level 5 conditions were defined as those which, at more severe grades of severity that cannot clearly be defined, may have a prolonged effect (one year or greater).
- Level 6 conditions were defined are those which do not on their own merit a Medical Card, but do merit a GP Visit Card.
- Level 7 conditions were defined as being conditions which do not of themselves merit a Medical Card or a GP Visit Card, but do merit a Long-term Illness book.

5.18 The outcome of the prioritisation exercise revealed that no condition received a unanimous ranking of Level 1 by the Expert Panel. Only two conditions received 100% support as Level 1 or Level 2, namely Progeria and Alzheimer's disease.

³⁴ The list of conditions was not intended to be comprehensive; rather it was intended to be a reasonable representation and cross-section of a variety of diseases, conditions and disabilities. The results presented are for the purposes of the exercise only, and are not a list of priority conditions.

5.19 Only 27 conditions were categorised and agreed by 75% or more of the Expert Panel as Level 1 or 2, and these are shown in Table 4 below.

Table 4 Exercise results

Expert Group Ranking as Level 1 or 2			
Mosaic/Non-mosaic Down syndrome	94%	Alzheimer's/dementia	100%
Progeria	100%	Muscular dystrophy*	75%
Thalidomide related*	75%	Paralysis – para/hemiplegia	94%
Brain cancer	75%	Amyotrophic lateral sclerosis	93%
Chronic lymphocytic leukaemia	75%	Huntington's disease	88%
Chronic myelogenous leukaemia	75%	Motor neurone disease	94%
Mesothelioma	75%	Spinal cord injury or paralysis	88%
Metastatic cancer	94%	Cystic fibrosis*	94%
Heart failure	75%	Lung transplant	80%
Symptomatic congenital heart	87%	Heart	93%
Haemophilia*	80%	Liver	79%
Sickle cell disease	81%	Kidney	79%
Multiple sclerosis (MS)	75%	Pancreas	79%
Bone marrow and stem cell	79%		

* Listed on Long Term Illness Scheme

5.20 The variability and lack of consensus in the exercise highlighted the enormous difficulty that any attempt (by any Expert Panel) at prioritisation will uncover. Some of the panel's difficulties are presented very honestly and openly in the following comments:

- *"I found it increasingly difficult to assign ticks to conditions beyond Level 1-3 and even within that I struggled, predominantly due to a lack of knowledge around the existence of definitions of severity or duration of condition."*
- *"I became increasingly uncomfortable doing the exercise, due to a sense of 'judging' in the absence of individualised information."*
- *"The distinction between lifelong and may have prolonged effect is difficult at times. [Defintion of] severity – this caused me much difficulty in deciding levels. What does clearly mean?"*
- *"Interesting exercise. Quite a few blank spaces left because ability to pay for care would lessen the impact of the disease on an individual. Also, because the label is so broad and the severity of the disease is so varied, someone with, for instance, cerebral palsy may be completely independent or totally dependent with huge medical needs."*
- *"For disabling genetic conditions, the majority of these are rare diseases. There may not be a treatment modality for many...among rare diseases it will be very important to differentiate between diseases that are treatable – whereby providing a Medical Card would prevent disability and further morbidity – and costs as, for example, in a common disease (Insulin-dependent diabetes.)"*
- *"The list of conditions is incomplete."*

5.21 Discussion amongst the Expert Panel also elicited some disease/condition-specific comments. As follows:

- For **Fragile X syndrome** – *“The need for a Medical Card will depend on how severely the patient is affected – how will we assess this?”*
- For **Down syndrome** – *“Equitable access to community services may be affected by availability of a Medical Card, so should they all be Level 1?”*
- For **Cerebral palsy** – *“This is such a diverse umbrella diagnosis ranging from very mild to severe, life-limiting illness – needs a way of assessing and using discretion.”*
- For **Foetal alcohol syndrome** – *“This is such a diverse umbrella diagnosis ranging from very mild to severe, life-limiting illness – needs a way of assessing and using discretion.”*
- For **Cancer** – *“The issue here is the duration.”*
- For **Benign brain tumours** – *“Some can be curable and some life-limiting and catastrophic, depending on their location.”*
- For **Angina** – *“It depends on the severity and equity of access to community services.”*
- For **Congenital heart disease** – *“Depends on the lesion and severity. Most require repeated surgeries and some are life-limiting.”*
- For **Colitis** – *“Depends on the severity.”*
- For **Glycogen storage disease** – *“Certainly, the paediatric cases need access to a Medical Card, to ensure equitable care.”*
- For **Diabetes mellitus** – *“Only if insulin dependent.”*
- For **Phenylketonuria** – *“PKU is a treatable and preventable condition and included in the Long Term Illness scheme. However, there is now a list of 81 more severe conditions that can be treated and thus prevent mental retardation which are not included in the Long Term Illness scheme (e.g. Urea cycle defects, Homocystinuria, Mitochondrial disorders).”*
- For **Morbid obesity** – *“Surely severity is the issue.”*
- For **Ehlers-Danlos** – *“There are several different types of Ehlers-Danlos, with differing severity.”*
- For **Mental disorders** – *“It depends on the severity and the underlying cause.”*

5.22 The experience and difficulty encountered by the Expert Panel in the conduct of this exercise is not unique and has been encountered by others. A dictionary of diagnoses for children in palliative care was developed in the UK, but produced a list that was reported as neither exhaustive, determinative nor definitive.³⁵

³⁵ http://www.togetherforshortlives.org.uk/assets/0000/7089/Directory_of_LLC_v1.3.pdf

5.23 At the outset of the exercise it was stated that the list of conditions provided for the Expert Panel exercise was diagnostically specific, non-descriptive and not comprehensive. It was understood and accepted that the feedback given was based on the conditions cited only. However, some of the Expert Panel made the valid point that if it was to proceed along the route of listing conditions, then all conditions would have to be considered. The size and complexity of such a task cannot be underestimated.

5.23.1 Version 10 of the WHO International Classification of Diseases identifies more than 14,400 different [disease] codes that can be further expanded to over 16,000 codes by using optional sub-classifications. The Inserm Orphanet Portal of rare diseases (citing incidences of 50/100,000 or less) published an index in May 2014 of some 595 rare diseases occurring in Europe.

5.23.2 The term 'medical condition' can also be understood to embrace more than just a medical disease or diagnosis. It can be taken to also include symptoms, such as angina, or a disability, such as a limb amputation.

5.23.3 A listing approach would be faced with the additional difficulties of accounting for the cumulative effect that more than one condition may have either on an individual patient, or when different members of a family are affected with one or more conditions or diseases.

5.23.4 There can be situations where a patient has a disability or impairment that does not necessarily have a specific name or diagnosis e.g. the frailty associated with simply growing old.

5.24 It was clear from the exercise that listing individual conditions posed a great difficulty for the entire panel. Some alternative approaches were suggested and debated at length.

5.24.1 An alternative approach might be to translate any decisions on conditions into themes, based on impairment and impact caused by the condition, rather than listing conditions individually. However, it was noted that this could create perverse incentives whereby a patient might then seek out a particular grading of severity (e.g. severe asthma as opposed to mild asthma) from different doctors, in order to meet the qualifying criteria for a Medical Card. This could also prove difficult for GPs and consultants – and for their professional relationship with their patients – as they might come under pressure to label a patient with a particular grade of condition.

- 5.24.2 Another alternative might be one that matched appropriate health services to meet the requirements of a medical condition. For example, a condition that affected speech should have full eligibility for speech and language therapy. However, it very quickly became clear that this approach too would be overly complex given that there are innumerable conditions, which would need to be matched by all the many different services available.
- 5.24.3 A discussion arose within the Expert Panel on the concept of a ceiling or cap on an individual's out-of-pocket expenses (i.e. fees) for GP attendances. This is essentially a model that accepts healthcare utilisation as a surrogate marker for burden of disease. While this is done in other jurisdictions, such an approach is administratively burdensome in terms of regulation and monitoring attendance with adherence to agreed clinical guidelines.
- 5.25 The problem of spectrum of disease clearly poses great difficulty. Some individuals with conditions such as Down syndrome and cerebral palsy can be relatively healthy and with limited health needs, and might not wish to be labelled by their condition or diagnosis.
- 5.26 The Expert Panel agreed that there are many conditions which can be very disabling – but do not have a 'voice' or 'face' in the consciousness of the public or the media. Such conditions include schizophrenia and many other mental health conditions.
- 5.27 Despite their qualifications and experience, some members of the Expert Panel were not as familiar with some of the conditions on the list, and they felt uncomfortable and somewhat demoralised in having to determine the level at which each condition should be ranked.
- 5.28 Discussion took place on the granting of Medical Cards for terminal illness, life-limiting conditions such as motor neurone disease (MND), and approaching end-of-life situations. While emergency Medical Cards are automatically granted within 24 hours of application, there did appear to be a perceived lack of clarity around this process. It was proposed that rather than wait for an emergency situation, there may be benefit in supporting a patient (given a terminal diagnosis) to make an application for a Medical Card early, in order to ensure access to all services and supports, and avoid having the added stress of having to apply for one when the disease has progressed and there are other priorities for the patient and their family.

5.29 Members of the Expert Panel expressed the strong view that specifying conditions for automatic Medical Card entitlement would be a retrograde step. As resources are finite, this would inevitably result in some individuals in our society being advantaged at the expense of others. Concern was raised as to how the Expert Panel could stand over any attempt at such a listing from an ethical perspective.

Overview of healthcare prioritisation in other countries

5.30 There is no internationally accepted list of disease states prioritised according to severity of impact of disease on the individual. A variety of different arrangements occur across countries, providing for differential eligibility for healthcare based on patient characteristics.^{36,37}

5.31 Many countries espouse universal access to healthcare for all citizens where, usually, some costs are borne by the patient at the time of consumption, but the bulk of costs come from a combination of compulsory insurance and tax revenues. Some programmes are paid for entirely out of tax revenues. In others, tax revenues are used either to fund insurance for the very poor or for those needing long-term chronic care. In insurance-based funding models, there may be differences in the ongoing insurance contributions and/or the co-payments required to access specific services such as pharmaceuticals, primary care etc. Most countries have a safety net whereby those on lower incomes have their insurance contributions covered by the State. For those on higher incomes, co-payment rates may be the same for all individuals, or there may be concessions based on specific patient characteristics. In Poland, for example, war veterans and blood donors are exempt from co-pays for prescriptions. A number of countries provide concessions for pregnant women.

5.32 A small number of countries have explicit morbidity-based exemptions. In Croatia, for example, patients with specific cancers and specific chronic mental health conditions are exempt from insurance contributions. In Italy, individuals exempt from co-payments for ambulatory [non-acute] care and pharmaceuticals include those with certain cancers, a diagnosis of HIV infection and those with rare diseases identified by epidemiological criteria defined in legislation. Patients with specific chronic diseases identified through high levels of healthcare consumption, as defined by legislation, are also exempt for certain services provided in accordance with clinical guidelines.

³⁶ Healthcare systems in transition (HIT) series, European Observatory on Health systems and Policies, World Health Organization, www.euro.who.int/en/about-us/partners/observatory/health-systems-in-transition-hit-series accessed August 2014

³⁷ Personal communication (M. Ryan): members of the European Network of HTA (EUnetHTA), August 2014

- 5.33 In a number of countries, concessions are indirectly related to burden of disease, as identified through high levels of healthcare consumption.
- 5.33.1 In Finland, there is a ceiling on co-payment of €679 per year for ambulatory care and €610 per year for pharmaceuticals.
- 5.33.2 In countries such as Austria, Belgium and Luxembourg the co-payment ceiling is adjusted by income. For example, in Luxembourg no individual's or family's total annual co-payment exceeds 2.5% of their annual income.
- 5.34 In other countries it is considered that setting limits on personal/family expenditure³⁸ based on their levels of healthcare consumption avoids difficulties with making expert judgements of severity of impact of a disease or co-existent diseases, where their impact varies with the individual patient and may change over time, on occasion quite quickly.
- 5.35 However, although attractive, the healthcare consumption approach constitutes an administrative burden, as it requires regulation of an application system, documentation and verification of appropriate use of healthcare, so as to ensure that they comply with accepted clinical guidelines.

³⁸ Often referred to as co-payments or out-of-pocket expenses

6. EXPERT PANEL – CONCLUSIONS

- 6.1 Medical Cards (or GP Visit Cards) awarded after an assessment of undue hardship or undue burden have become associated with the phrase ‘discretionary Medical Cards’. The definition of discretionary is misunderstood and undoubtedly a cause of confusion. Under the current system there is no difference between Medical Cards (or GP Visit Cards) awarded purely on the basis of income being below the guidelines, and Medical Cards (or GP Visit Cards) awarded after an assessment of undue hardship or undue burden.
- 6.2 Although imperfect, there was general consensus among the Expert Panel that to a certain level the current granting of Medical Cards on a discretionary basis does work, and that cards are awarded on this basis whenever it is possible to do so. In making the decision, PCRS staff members in general, with the consent of the individual, liaise with the applicant's doctors, allied health professionals and others.
- 6.2.1 A sample of 25 Medical Cards approved on discretionary grounds was examined as part of the most recent audit report published by the Comptroller and Auditor General (2013). It states that in the majority of cases, the cards were awarded on the basis of significant expenditure in relation to medical costs.³⁹
- 6.3 There is clear evidence that the current Medical Card application system is inconsistent, poorly understood and inefficient.³⁹
- 6.3.1 During 2012, about 22% (or >1 in 5) of applications submitted by individuals were incomplete.
- 6.3.2 The Expert Panel was told that there are times when patients, GPs and consultants do not provide sufficient information on medical forms to allow informed decisions. This is consistent with the Comptroller and Auditor General’s audit report (2012) finding that while letters from the GP provided details of the illness of the individual, there was no attempt to quantify the medical costs involved and therefore provide evidence that these costs would cause financial hardship to the individual.

³⁹ The Comptroller and Auditor General’s *Report on the accounts of the public services 2012* (published September 2013)

- 6.3.3 Prior to the centralisation of the application process it was recognised that assessment for eligibility for Medical Cards was not consistent between the 100 offices conducting the reviews, and some card holders held Medical Cards for long and unpredictable periods, in some cases, for many years.
- 6.3.4 There is a high level of non-response to renewal notices. The shorter the validity period for a Medical Card and/or renewal notice the greater the risk of non-response. In 2012, 10.7% of card holders had not responded to renewal, and the Medical Card lapsed as a result. Undoubtedly, while some of those receiving the renewal notice may not respond because they are aware that they no longer satisfy the eligibility criteria, there is no doubt that some non-responses can be attributed to Medical Card holders failing to understand what they are required to do and the timeframe in which they have to do it.
- 6.3.5 In the period January to June 2014 approximately 4,000 calls and queries were received by the PCRS per day and over 826 Parliamentary Questions (25% of the HSE total) were forwarded to the PCRS. This is clearly consuming resources that could otherwise be more patient focussed and utilised in processing applications.
- 6.4 There appears to be an inconsistent interpretation and understanding of the requirement to have a Medical Card to access community primary care services such as physiotherapy, occupational therapy, speech and language therapy, public health nursing etc.
- 6.5 Use of a Medical Card as the qualifying criterion or allocation mechanism for access to aids and appliances will inevitably mean inaccessibility for non-Medical Card holders who have potentially greater clinical need.
- 6.6 The request for, and scrutiny of, personal financial data can be an upsetting exercise for individuals being assessed and reviewed for Medical Cards. However, it remains the only mechanism available to the health service to fairly and equitably assess undue hardship or burden. The health service is in the difficult if not invidious position of responding to calls to reduce patient distress by using less frequent and less detailed audits, while at the same time it is being pressed by the Comptroller and Auditor General to perform more audits and greater scrutiny on behalf of the taxpayer.⁴⁰

⁴⁰ The Comptroller and Auditor General's *Report on the accounts of the public services 2012*. Recommendation 22.6: The HSE should conduct reviews of random samples of card holders on an annual basis.

- 6.7 There continues to be a perceived lack of transparency with the application and decision-making process, which needs to be more explicit, transparent and fair. Involvement of representatives of the general population in deliberating on the ethical and social issues arising would ensure that the importance and value of a fair and transparent consultative public process for access to medical services could be incorporated.
- 6.8 Under revised rules issued in 2011, standard Medical Cards are now normally valid for three years in the case of people aged under 66 years, and for four years for persons aged 66 or over. The Expert Panel would have to question whether the concept of renewal of Medical Cards is understood and has been adequately communicated given that until very recently (2011) some individuals were issued with Medical Cards valid for up to 20 years.
- 6.8.1 In the context of individuals awarded a Medical Card on the basis of discretion, the renewal process needs to be handled sensitively.
- 6.9 The Expert Panel has concluded that attempting to list and prioritise conditions for full Medical Card eligibility is not possible and risks (a) inequity by diagnosis and (b) the continuation of a historical tendency of a fragmented and short-sighted approach to resolving universal access to the full suite of primary care services.

7. EXPERT PANEL RECOMMENDATIONS

- 7.1 The Expert Panel recommends that in the absence of international objective and reproducible methods of measuring burden of disease and illness it is neither feasible nor desirable to list conditions in priority order for Medical Card eligibility. A listing approach risks inequity by diagnosis and a further fragmentation of services.
- 7.2 The Expert Panel recommends that in the context of an ethical approach to the allocation of finite resources the current system as it stands is not without its merits for the great majority.
- 7.3 The Expert Panel recommends that the operational deficiencies that currently exist are addressed using an ethical principles framework approach. There are opportunities for significant improvements in the current system using this approach to (a) ensure that any priority setting process is more transparent; (b) involves all stakeholders; (c) delivers similar outcomes for those in broadly similar circumstances; (d) takes account of health outcomes in the context of a finite health budget, and (e) is sufficiently flexible and attentive to the most vulnerable individuals and those with critical needs.
- 7.4 The Expert Panel recommends that the calculation of financial hardship or means testing should be the primary responsibility of a Government Department or body other than the health service.
- 7.5 The Expert Panel recommends that the role of the health service would appear to be more appropriately qualified to use third-party provided means-tested information, and to define and then identify 'medical hardship' or 'burden of disease'.
- 7.6 The Expert Panel recommends the publication of the governance structure of the PCRS detailing responsibility and accountability structures for the administration of the Medical Card Scheme.
- 7.7 The Expert Panel recommends consideration of the separation of the PCRS Medical Card Scheme from the PCRS re-imburement [of Primary Care Contractors] function.
- 7.8 The Expert Panel recommends that financial hardship or means testing should remain the main discriminator for selecting the large majority of those eligible for a Medical Card, which is consistent with other health systems in the European Union.
- 7.9 The Expert Panel recommends that, where possible, the Medical Card system should be made simpler and more explicit and that there needs to be a comprehensive suite of communication and education materials to assist individuals and healthcare professionals with the Medical Card application process and the concept of renewal.

- 7.10 The Expert Panel recommends the uncoupling of non-medical benefits from Medical Cards. Access to these non-medical benefits should however remain as a means-tested support, but should not be an automatic entitlement determined by an individual's Medical Card status.
- 7.11 The Expert Panel recommends that access to primary care services (physiotherapy, occupational therapy, speech and language therapy etc.) should be consistent across the country. Prioritisation should be on the basis of clinical need – independent of the possession of a Medical Card – defined after triage into categories of urgent or routine, and thereafter seen in chronological order within these categories.
- 7.12 The Expert Panel recommends that an individual's Medical Card status should not be the sole qualifying criterion for access to aids and appliances.
- 7.13 The Expert Panel recommends that for individuals awarded a Medical Card incorporating discretion, the renewal process needs to be handled with a greater degree of sensitivity.
- 7.14 The Expert Panel recommends that, as a working principle, discretionary Medical Cards should only be provided to the individual with the index condition, and not to the entire family.
- 7.15 The Expert Panel recommends that if a discretionary Medical Card award involves any terminal or life-limiting condition, such as motor neurone disease, then it should be granted for the remainder of life and should not require the individual or their family to undergo a standard review process every three years.
- 7.16 The Expert Panel recommends that society's desire to exercise a more compassionate and supportive approach for those with a combination of financial and/or medical hardship be addressed by extending the discretionary decision-making process beyond financial hardship to include an assessment of the burden of a medical condition(s).
- 7.17 The Expert Panel recommends the involvement of the general population, to deliberate on the ethical and social issues arising from access to healthcare in the context of finite resources.
- 7.18 The Expert Panel recommends the incorporation of a new Strategic Clinical Advisory Group into the PCRS governance structure, with broad and experienced clinical, lay and administrative representation and access to expert opinions when required. It is the view of the Expert Panel that this is required in order to give clinical oversight and guidance to the operation of a more compassionate and trusted Medical Card system which can strive to ensure that the relatively small percentage of cases requiring the recognition of the burden of a medical condition(s) over and above financial hardship can be accommodated.

- 7.19 The Expert Panel recommends that the initial work programme for the Strategic Clinical Advisory Group should firstly address the development of a strategic framework for assessment and measurement of the burden of disease; secondly, address the development of appropriate operational guidelines for Medical Assessors and Decision Officers, and thirdly, address the development of appropriate key performance indicators (KPIs) to support clinical oversight and performance assurance.
- 7.20 The Expert Panel recommends that the significant challenges to be faced in extending the discretionary decision to include an assessment of the burden of a medical condition(s) must be acknowledged by all. These include the fact that professional judgement in the assessment of medical hardship can never be completely objective, fully transparent and totally reproducible; the methodology to underpin an enhanced discretionary process requires an options appraisal of existing comparators of the burden of disease and their measurement including healthcare consumption; a realistic timeframe to examine the feasibility, including costings, of such a process; and finally, the additional resourcing that would be required to increase clinical assessment capacity including doctors, nurses and allied health professionals, in order to provide a greater degree of scrutiny and personalised clinical judgement.
- 7.21 The Expert Panel recommends that, in terms of maximising population health gain, a priority for the health service should be to use the preceding recommendations as a stepping stone to the implementation of the first phase of the Government's Primary Care reform programme, providing free GP care for all, with the aim of further ensuring universal access to the full spectrum of primary care services as a matter of course and thereby aligning the health service in Ireland with health systems in other EU Member States.
- 7.22 The Expert Panel recommends that an annual report of the implementation status of each of the recommendations contained in this report should be presented by the HSE National Director of Primary Care to the Director General of the HSE.

APPENDIX 1: EXPERT PANEL EXERCISE⁴¹

	Percentage of individuals selecting:								
	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6	Level 7	No benefit	Don't know
Disabling genetic disorders									
Fragile X syndrome	56%	13%	0%	19%	6%	0%	0%	6%	0%
Mosaic/Non-mosaic Down syndrome	94%	0%	6%	0%	0%	0%	0%	0%	0%
Phenylketonuria (PKU)	44%	13%	0%	19%	0%	0%	0%	19%	6%
Progeria	88%	0%	0%	0%	0%	0%	0%	0%	13%
Trisomy X syndrome (XXX Syndrome)	38%	6%	0%	31%	0%	0%	6%	13%	6%
Birth disorders									
Caudal regression syndrome	25%	25%	19%	13%	0%	0%	0%	13%	6%
Cerebral palsy	38%	19%	0%	13%	0%	0%	6%	19%	6%
Foetal alcohol syndrome	19%	25%	0%	38%	0%	0%	6%	0%	13%
Hydrocephalus	25%	31%	0%	13%	0%	0%	6%	13%	13%
Thalidomide related	38%	38%	0%	6%	0%	0%	0%	19%	0%
Cancer									
Acute leukaemia	19%	13%	38%	6%	0%	0%	13%	13%	0%
Benign brain tumours	6%	6%	31%	31%	6%	0%	0%	19%	0%
Brain cancer	50%	25%	19%	6%	0%	0%	0%	0%	0%
Chronic lymphocytic leukaemia	19%	56%	13%	13%	0%	0%	0%	0%	0%
Chronic myelogenous leukaemia (CML)	31%	44%	13%	13%	0%	0%	0%	0%	0%
Colon cancer	6%	19%	56%	19%	0%	0%	0%	0%	0%
Lymphedema	13%	25%	25%	25%	0%	0%	0%	13%	0%
Lymphoma	19%	25%	50%	6%	0%	0%	0%	0%	0%
Mesothelioma	56%	19%	19%	6%	0%	0%	0%	0%	0%
Metastatic cancer	94%	0%	0%	6%	0%	0%	0%	0%	0%
Myelofibrosis (Myeloproliferative syndrome)	38%	13%	13%	19%	0%	0%	0%	13%	6%
Cardiovascular conditions									
Aneurysm of aorta or major branches	0%	19%	13%	19%	0%	0%	13%	25%	13%
Angina	6%	25%	13%	6%	13%	0%	25%	13%	0%
Atrial fibrillation	6%	13%	13%	25%	13%	0%	13%	13%	6%
Cardiomyopathy	31%	31%	13%	13%	0%	0%	6%	6%	0%
Congenital heart disease	19%	44%	6%	19%	6%	0%	0%	6%	0%
Chronic venous insufficiency	0%	6%	0%	19%	6%	0%	6%	44%	19%
Deep vein thrombosis	0%	0%	6%	13%	25%	0%	19%	25%	13%
Fibromuscular dysplasia	0%	6%	0%	13%	6%	13%	6%	38%	19%

⁴¹ Red font = Conditions currently covered under the LTI Scheme; Light green cell = Level which has been selected the most times per condition

	Percentage of individuals selecting:								
	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6	Level 7	No benefit	Don't know
Giant cell arteritis	0%	6%	0%	13%	6%	0%	13%	31%	31%
Heart failure	31%	44%	13%	6%	0%	0%	0%	6%	0%
High blood pressure (Hypertension)	0%	13%	6%	0%	0%	25%	19%	25%	13%
Ischemic heart disease	0%	31%	13%	13%	6%	13%	6%	19%	0%
Peripheral arterial disease + claudication, rest pain or gangrene	31%	31%	6%	6%	6%	0%	0%	13%	6%
Postural orthostatic tachycardia syndrome (POTS)	0%	0%	6%	13%	13%	6%	13%	25%	25%
Prolonged QT syndrome	13%	6%	0%	13%	0%	13%	6%	31%	19%
Raynaud's disease	0%	13%	0%	13%	25%	13%	13%	19%	6%
Recurrent arrhythmias	6%	6%	6%	25%	13%	0%	6%	25%	13%
Sinus bradycardia	0%	6%	0%	13%	25%	6%	0%	38%	13%
Symptomatic congenital heart disease	44%	38%	0%	6%	0%	0%	0%	6%	6%
Takayasu's arteritis	6%	19%	0%	19%	6%	0%	0%	25%	25%
Digestive tract problems,									
Bowel incontinence	19%	13%	6%	13%	13%	0%	13%	13%	13%
Cirrhosis	31%	19%	19%	19%	0%	6%	0%	6%	0%
Colitis	6%	6%	19%	31%	19%	6%	0%	6%	6%
Crohn's disease	25%	31%	6%	19%	0%	13%	0%	6%	0%
Diverticulitis	0%	6%	6%	19%	13%	6%	13%	31%	6%
Glycogen storage disease	38%	19%	0%	6%	0%	0%	0%	19%	19%
Hepatitis	6%	13%	25%	19%	6%	6%	0%	19%	6%
Inflammatory bowel disease	25%	31%	0%	31%	0%	6%	0%	6%	0%
Irritable bowel	0%	0%	6%	13%	6%	19%	13%	38%	6%
Primary biliary cirrhosis	50%	19%	6%	0%	0%	0%	0%	19%	6%
Primary sclerosing cholangitis	44%	19%	13%	0%	0%	0%	0%	19%	6%
Short bowel syndrome	25%	0%	6%	19%	6%	0%	0%	31%	13%
Wilson's disease	38%	19%	0%	6%	0%	0%	0%	25%	13%
Endocrine disorders									
Adrenal gland disorders	13%	0%	13%	19%	6%	0%	0%	38%	13%
Diabetes mellitus	44%	13%	13%	0%	0%	0%	6%	25%	0%
Diabetes insipidus	25%	19%	6%	6%	6%	0%	6%	25%	6%
Hyperparathyroidism	6%	6%	13%	13%	6%	13%	13%	31%	0%
Hyperfunction of Adrenal Cortex	6%	6%	13%	19%	6%	6%	6%	31%	6%
Morbid obesity	6%	0%	25%	25%	0%	6%	6%	25%	6%
Pituitary gland disorders	6%	0%	25%	19%	6%	6%	0%	31%	6%
Female disorders									
Endometriosis	0%	0%	6%	13%	19%	0%	13%	38%	13%
Haematological disorders									
Aplastic anaemia	44%	13%	6%	6%	6%	0%	0%	6%	19%

	Percentage of individuals selecting:								
	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6	Level 7	No benefit	Don't know
Budd-Chiari syndrome	6%	19%	31%	6%	0%	0%	0%	19%	19%
Coagulation defects and Haemophilia	38%	25%	0%	13%	0%	0%	6%	13%	6%
Chronic anaemia	13%	6%	13%	6%	0%	0%	0%	38%	25%
Chronic granulocytopenia	13%	0%	6%	19%	6%	0%	0%	38%	19%
Chronic thrombocytopenia	13%	0%	6%	19%	6%	0%	0%	38%	19%
Gilbert's syndrome	6%	0%	6%	0%	6%	6%	6%	50%	19%
Haemochromatosis	19%	31%	6%	13%	0%	6%	0%	19%	6%
Haemophilia	69%	6%	0%	0%	0%	0%	13%	6%	6%
Macroglobulinemia	6%	6%	19%	6%	6%	0%	0%	31%	25%
Multiple myeloma	44%	13%	13%	13%	6%	0%	0%	6%	6%
Polycythemia vera	6%	19%	13%	19%	6%	0%	0%	19%	19%
Sickle cell disease	38%	44%	0%	6%	0%	0%	0%	13%	0%
Immune system disorders									
Epstein-Barr virus	0%	0%	0%	13%	13%	6%	6%	50%	13%
Dermatomyositis	0%	6%	31%	6%	13%	0%	0%	25%	19%
Guillain-Barré syndrome	0%	6%	50%	13%	6%	0%	6%	13%	6%
Human Immunodeficiency Virus (HIV)	56%	13%	13%	13%	0%	0%	0%	6%	0%
Lupus	38%	31%	0%	19%	6%	0%	0%	6%	0%
Multiple Sclerosis (MS)	50%	25%	6%	6%	0%	6%	0%	6%	0%
Polymyositis	13%	13%	0%	25%	6%	0%	0%	31%	13%
Scleroderma	31%	31%	0%	19%	0%	0%	0%	13%	6%
Sjögren's syndrome	13%	19%	6%	31%	0%	0%	0%	19%	13%
Systemic vasculitis	13%	6%	6%	31%	13%	0%	0%	19%	13%
Undifferentiated and mixed connective tissue Disease	6%	25%	6%	19%	6%	0%	0%	19%	19%
Kidney disease and genitourinary problems									
Interstitial cystitis	6%	0%	6%	13%	19%	6%	0%	31%	19%
Kidney failure	44%	25%	0%	19%	0%	0%	0%	6%	6%
Nephrotic syndrome	19%	19%	0%	19%	13%	0%	0%	25%	6%
Urinary incontinence	6%	6%	19%	13%	13%	0%	13%	25%	6%
Mental health disorders									
Alzheimer's disease	75%	25%	0%	0%	0%	0%	0%	0%	0%
Anxiety disorder	0%	0%	13%	13%	19%	6%	13%	31%	6%
Attention deficit hyperactivity disorder	0%	6%	31%	13%	13%	6%	6%	25%	0%
Asperger syndrome	25%	13%	0%	6%	13%	0%	13%	31%	0%
Autism	25%	38%	0%	25%	6%	0%	6%	0%	0%
Bipolar disorder	6%	44%	6%	13%	13%	0%	0%	19%	0%
Chronic insomnia	0%	6%	0%	13%	0%	13%	6%	50%	13%
Depression	0%	6%	25%	31%	6%	0%	0%	25%	6%

	Percentage of individuals selecting:								
	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6	Level 7	No benefit	Don't know
Drug addiction	6%	13%	13%	6%	13%	13%	6%	25%	6%
Dysthymia	0%	0%	6%	6%	13%	6%	6%	44%	19%
Eating disorders	0%	13%	25%	19%	19%	0%	6%	13%	6%
Mental handicap	25%	31%	6%	6%	6%	0%	6%	19%	0%
Mental illness under 16	6%	19%	19%	6%	19%	0%	6%	19%	6%
Mood disorders	0%	0%	13%	13%	13%	6%	0%	44%	13%
Obsessive compulsive disorder	6%	0%	13%	6%	19%	6%	0%	44%	6%
Organic mental disorders	13%	19%	6%	13%	13%	0%	0%	25%	13%
Panic attacks	0%	6%	6%	19%	19%	6%	0%	31%	13%
Post-traumatic stress disorder	0%	6%	0%	19%	19%	19%	0%	31%	6%
Somatoform disorders	0%	6%	0%	19%	19%	0%	6%	38%	13%
Schizophrenia	50%	19%	6%	13%	0%	0%	0%	13%	0%
Musculoskeletal problems									
Ankylosing spondylitis	13%	25%	19%	25%	0%	0%	0%	13%	6%
Avascular necrosis	6%	6%	13%	19%	6%	6%	0%	31%	13%
Carpal tunnel syndrome	0%	0%	6%	13%	13%	6%	13%	38%	13%
Clubfoot	0%	6%	6%	19%	19%	0%	6%	38%	6%
Coccydynia	0%	0%	6%	19%	6%	0%	6%	50%	13%
Complex regional pain syndrome	6%	6%	13%	19%	13%	6%	0%	25%	13%
Degenerative disc disease	0%	13%	6%	25%	13%	0%	6%	31%	6%
Dupuytren's contracture	0%	0%	6%	0%	0%	19%	6%	56%	13%
Ehlers-Danlos	6%	31%	0%	13%	6%	0%	6%	25%	13%
Fibromyalgia	0%	0%	6%	38%	6%	0%	6%	25%	19%
Fracture of an upper extremity	0%	0%	6%	6%	0%	6%	13%	50%	19%
Fracture of the femur, tibia, pelvis, or one or more of the tarsal bones	0%	0%	6%	6%	0%	6%	13%	50%	19%
Gout	0%	0%	6%	6%	6%	13%	6%	44%	19%
Growth impairment disorders	6%	25%	0%	0%	6%	6%	0%	38%	19%
Herniated disc, ruptured disc	0%	6%	19%	25%	6%	0%	6%	31%	6%
Limb amputation	44%	0%	13%	19%	0%	0%	0%	19%	6%
Lumbar stenosis	0%	0%	13%	0%	13%	6%	0%	50%	19%
Major dysfunction of a joint	0%	0%	19%	13%	6%	6%	0%	38%	19%
Muscular dystrophy	69%	6%	0%	0%	0%	0%	19%	6%	0%
Myasthenia gravis	31%	13%	0%	6%	6%	0%	0%	38%	6%
Traumatic back pain	0%	0%	6%	19%	13%	0%	6%	38%	19%
Traumatic neck pain/whiplash	0%	0%	6%	13%	6%	0%	6%	50%	19%
Osteoarthritis	0%	6%	19%	19%	25%	0%	6%	25%	0%
Paralysis – para/hemiplegia	69%	25%	0%	6%	0%	0%	0%	0%	0%
Reflex sympathetic dystrophy	0%	13%	6%	19%	19%	0%	0%	31%	13%

	Percentage of individuals selecting:								
	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6	Level 7	No benefit	Don't know
Rheumatoid arthritis	19%	44%	6%	25%	6%	0%	0%	0%	0%
Scoliosis	0%	6%	19%	13%	13%	13%	6%	31%	0%
Spina bifida	13%	50%	0%	19%	0%	0%	6%	13%	0%
Spinal arachnoiditis	6%	0%	0%	13%	6%	0%	6%	44%	25%
Spinal cord injury	25%	19%	6%	31%	0%	0%	0%	19%	0%
Torn ACL	0%	0%	6%	6%	0%	6%	13%	50%	19%
Neurological disorders									
Acoustic neuroma	8%	0%	25%	8%	8%	8%	0%	33%	8%
Amyotrophic lateral sclerosis (ALS)	83%	0%	0%	0%	0%	0%	0%	17%	0%
Bell's palsy	0%	0%	8%	17%	17%	8%	8%	33%	8%
Cerebral adrenoleukodystrophy (X-ALD)	6%	0%	19%	6%	13%	13%	0%	25%	19%
Cerebral palsy	81%	6%	0%	0%	0%	0%	0%	6%	6%
Complex regional pain syndrome (CRPS)	0%	0%	6%	19%	19%	6%	6%	38%	6%
Charcot-Marie-Tooth disease	50%	19%	6%	0%	0%	0%	0%	19%	6%
Dystonia	31%	13%	0%	31%	6%	0%	6%	6%	6%
Dysautonomia	6%	6%	19%	19%	13%	0%	6%	19%	13%
Epilepsy and seizure disorders	13%	13%	6%	19%	0%	0%	0%	38%	13%
Essential tremor	0%	19%	0%	38%	6%	6%	0%	19%	13%
Huntington's disease	13%	19%	0%	25%	6%	0%	0%	25%	13%
Ilioinguinal neuralgia	19%	25%	13%	25%	6%	0%	6%	6%	0%
Migraine	0%	0%	0%	6%	6%	6%	13%	56%	13%
Narcolepsy	8%	8%	0%	17%	25%	8%	0%	25%	8%
Motor neurone disease	94%	0%	0%	0%	0%	0%	0%	6%	0%
Multiple sclerosis (MS)	31%	38%	6%	13%	0%	0%	0%	13%	0%
Parkinson's disease	25%	38%	13%	13%	0%	0%	0%	13%	0%
Peripheral neuropathy	6%	13%	13%	31%	13%	0%	0%	19%	6%
Pick's disease and other rare neurodegenerative diseases	56%	13%	0%	0%	6%	0%	0%	19%	6%
Post-polio syndrome	25%	19%	6%	25%	6%	0%	0%	13%	6%
Reflex sympathetic dystrophy (RSD)	6%	0%	0%	13%	19%	6%	6%	38%	13%
Shingles and postherpetic neuralgia (PHN)	0%	0%	0%	19%	19%	0%	6%	44%	13%
Spinal cord injury or paralysis	69%	19%	0%	13%	0%	0%	0%	0%	0%
Stroke (Cerebrovascular accident)	19%	19%	25%	31%	0%	0%	0%	6%	0%
Syringomyelia	13%	0%	25%	25%	6%	0%	0%	31%	0%
Transient ischemic attacks (TIAs)	0%	6%	19%	25%	19%	0%	0%	25%	6%
Transverse myelitis	13%	6%	25%	13%	0%	0%	6%	25%	13%
Trigeminal neuralgia and face pain	0%	0%	19%	25%	6%	0%	0%	31%	19%
Respiratory illness									
Asthma	6%	19%	25%	19%	19%	6%	0%	0%	6%

	Percentage of individuals selecting:								
	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6	Level 7	No benefit	Don't know
Bronchiectasis	6%	13%	13%	19%	19%	6%	0%	13%	13%
Chronic obstructive pulmonary disease (COPD)	6%	19%	25%	31%	0%	6%	0%	6%	6%
Chronic restrictive ventilatory disease	6%	19%	13%	25%	0%	6%	0%	19%	13%
Chronic venous insufficiency	0%	13%	6%	6%	6%	6%	6%	38%	19%
Cystic fibrosis	94%	0%	0%	0%	0%	0%	6%	0%	0%
Emphysema	19%	31%	19%	19%	0%	0%	0%	13%	0%
Lung transplant	75%	0%	13%	0%	0%	6%	0%	0%	6%
Mycobacterial, mycotic, and other chronic persistent infections of the lungs	6%	25%	19%	13%	13%	0%	0%	13%	13%
Pneumoconiosis	0%	25%	13%	13%	6%	6%	0%	25%	13%
Pulmonary tuberculosis	6%	6%	25%	19%	19%	0%	0%	6%	19%
Sarcoidosis	6%	6%	31%	13%	6%	0%	0%	25%	13%
Sleep apnoea	6%	6%	6%	13%	25%	6%	0%	31%	6%
Sleep-related breathing disorders	0%	0%	6%	19%	25%	6%	0%	31%	13%
Senses and speech issues									
Acoustic neuroma	6%	0%	13%	13%	13%	0%	0%	44%	13%
Auditory processing disorder	0%	6%	6%	13%	13%	0%	0%	44%	19%
Loss of speech	19%	6%	13%	6%	6%	6%	0%	25%	19%
Macular degeneration	13%	13%	19%	25%	0%	0%	0%	25%	6%
Meniere's disease	0%	0%	13%	19%	19%	0%	6%	38%	6%
Hearing loss	6%	6%	13%	19%	6%	0%	6%	31%	13%
Retinitis pigmentosa	31%	6%	6%	19%	0%	0%	6%	25%	6%
Vision loss	19%	6%	13%	13%	0%	6%	6%	25%	13%
Skin disorders									
Bullous diseases	13%	6%	31%	0%	13%	0%	0%	19%	19%
Burns	0%	0%	25%	19%	6%	0%	0%	31%	19%
Cellulitis	0%	0%	6%	19%	0%	13%	6%	44%	13%
Chronic skin diseases	0%	0%	13%	19%	19%	6%	0%	31%	13%
Dermatitis	0%	6%	6%	13%	13%	0%	6%	38%	19%
Genetic photosensitivity disorders	0%	6%	6%	13%	13%	13%	0%	31%	19%
Hidradenitis suppurativa	0%	6%	0%	0%	19%	6%	0%	50%	19%
Ichthyosis	13%	13%	0%	6%	6%	13%	6%	31%	13%
Psoriasis	0%	6%	13%	25%	6%	6%	6%	25%	13%
Transplant recipients or awaiting									
Heart	81%	0%	6%	0%	0%	0%	0%	0%	13%
Liver	69%	0%	19%	0%	0%	0%	0%	0%	13%
Kidney	69%	0%	19%	0%	0%	0%	0%	0%	13%
Pancreas	69%	0%	19%	0%	0%	0%	0%	0%	13%
Bone marrow and stem cell	69%	0%	19%	0%	0%	0%	0%	0%	13%

Appendix 2: Expert Panel Membership

Membership

- > **Chair: Professor Frank Keane**, Clinical Lead, National Clinical Programme for Surgery and Past President of the Royal College of Surgeons in Ireland
- > **Vice-Chair: Dr Alan Smith**, Medical Director — Screening Policy, National Cancer Screening Service

Members (in alphabetical order)

- > **Ms Emma Benton**, Therapy Professions Advisor, Clinical Strategy and Programmes Division, HSE
- > **Dr Aine Carroll**, National Director, Clinical Strategy and Programmes, HSE
- > **Dr Mary Devins**, Consultant Paediatrician and Paediatrician in Palliative Care, Our Lady's Children's Hospital, Crumlin
- > **Dr John Fitzsimons**, Consultant Paediatrician and Clinical Director for Quality Improvement, Quality and Patient Safety Division, HSE
- > **Dr Mary Gray**, General Practitioner, Limerick
- > **Dr Johanna Joyce**, Principal Medical Officer, HSE Midlands
- > **Dr Bryan Lynch**, Consultant in Paediatric Neurology, Children's University Hospital, Temple Street
- > **Dr John Macfarlane**, Consultant in Rehabilitation Medicine
- > **Ms Marion Meany**, Assistant National Director, Disability Services, Social Care Division, HSE
- > **Dr Austin O'Carroll**, General Practitioner, Dublin
- > **Dr Susan O'Reilly**, Director, National Cancer Control Programme
- > **Dr Diarmuid O'Shea**, Clinical Lead, National Clinical Programme for Older People and Consultant in Elderly Medicine
- > **Ms Marie Price Bolger**, Chief Executive of TRUSTUS. Chair of the local Patient and Community Advisory Group, Tallaght
- > **Ms Virginia Pye**, Director of Public Health Nursing, Longford/Westmeath HSE Midlands
- > **Dr Karen Ryan**, Clinical Lead, National Clinical Programme for Palliative Care, HSE
- > **Dr Máirín Ryan**, Director of Health of Technology Assessment, Health Information Quality Authority
- > **Dr Mary Sheehan**, Chairperson, Irish College of General Practitioners and General Practitioner, Laois
- > **Professor Eileen Treacy**, Clinical Lead, National Clinical Programme for Rare Diseases and Consultant in Metabolic Disorders, HSE
- > **Dr John Whately**, General Practitioner, Dundalk
- > **Dr Peter Wright**, Population Health, Health and Wellbeing Division
- > **Dr Margo Wrigley**, Group Clinical Lead, Mental Health Division and Consultant in Old Age Psychiatry, HSE

Secretary: Ms Helen Kelly, Office of the National Director, Primary Care HSE

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