

ACCESS TO MEDICINES: a cross-party dialogue

Background

Access to medicines has attracted significant public attention in recent months and years, and several high-profile campaigns have been organised to lobby for positive reimbursement decisions. Patients and campaigners often feel that they are forced to adopt this course of action due to institutional failures to ensure a consistent, fair and transparent process for the assessment and reimbursement of new medicines, particularly in the interactions between the HSE and the Department of Health in the post-Health Technology Assessment phase.

The patient community has long advocated for system reform in this area, but until recently, national health agencies have remained largely unresponsive. In an effort to catalyse change, patient-led organisations IPPOSI and MRCG published two 'Drug Iceberg' reports in [August 2017](#) and [February 2018](#). These reports make specific recommendations to different stakeholder groups, including to the government, the pharmaceutical industry, regulators and patient organisations. It is our hope that these recommendations can act as a starting point to come together – in the spirit of partnership – to ensure that Irish patients have access to the right treatment at the right time both today and in the future.

The patient community has been heartened by the response in 2018 from political and media circles. In January 2018, [the Taoiseach addressed the issue of the rising cost of medicines in a speech to the European Parliament](#); in February, the [Joint Committee on Health published a report on orphan drugs](#); in March [Fianna Fail tabled a Bill on orphan medicines access](#) and the [Joint Committee on Health debated the EU proposal to engage in joint clinical assessments](#); in April the [Sunday Business Post dedicated an article to the plight of patients seeking access to new medicines](#); in June [Ireland joined the BeNeLuxA initiative to negotiate more affordable access to medicines](#).

Today, we seek to work in partnership with you to join up some of the dots, and we invite you to open a dialogue with us on the topic of access to medicines which we hope can continue to build upon the work to find sustainable solutions for our health system.

Rationale for dialogue

We need political leadership to address challenges around access to new and improved medicines – national agencies are not making the necessary changes fast enough to meet the best interests of patients. We believe political parties – in government and in opposition – can play an important role in driving forward process reform as well as in monitoring performance.

We know that many of you are dealing with access to medicines issues in your interactions with constituents, and we predict that the volume of casework of this nature is likely to only increase in the months and years to come. We want you to be in a position to help patients in your constituency and across Ireland, including people who will be patients in the future. We ask, therefore, that you

dedicate your efforts to advocating for a properly resourced, accountable and participatory assessment and reimbursement *process*, and not just for a resolution for the *individual* patients that come to your offices.

It is our hope that this meeting can:

- open a dialogue on the topic of access to medicines between patients and political parties; one which we can continue in the months and years to come
- secure a commitment from political parties to consider access to medicines in their upcoming health policy development, including future election manifestos
- explore the role of the Joint Oireachtas Committee on Health in monitoring the ongoing access to medicines situation

Patient perspectives

We believe that understanding the basic patient 'ask' is not difficult – patients want access to the best medicines, and they want it in the shortest timeframe possible. We recognise that creating the circumstances needed for this to happen is challenging.

- **NEW STRATEGY:** Decisions about access to medicines must not be made on the basis of political expediency, rudimentary assessments based on cost or emotive lobbying. We need to be careful of quick fixes and ad hoc solutions. For the health needs of all patients to be met, both now and in the future, we should develop a comprehensive, multi-sectoral, sustainable plan – a **National Medicines Strategy**. The Strategy should seek to secure cross-party support and its implementation should be progressed by successive Governments.
- **INCREASED FUNDING:** Although competition for national resources remains high, health budgets must increase to meet the needs of a growing community of patients living in Ireland with chronic and/or rare diseases. We cannot expect zero-growth budgets to be able to deliver the healthcare needed. We should allocate more funding to the Primary Care Reimbursement Service and we should undertake a system-wide review to identify where efficiencies can be made.
- **MORE TRANSPARENCY:** National agencies tasked with decisions about access to medicines must be accountable to the public – both the patient and the tax-payer. We cannot continue to work behind closed doors, nor can we allow our healthcare to lag ever-further behind our European counterparts. Decisions must be made within a pre-determined process which is fit-for-purpose and designed in consultation with relevant health stakeholders. Institutional shortcomings must be identified and solutions put in place to ensure that no patient is unduly denied or delayed access to life-changing and/or life-saving new medicines. A **Ministerial Directive** should require the NCPE and HSE to deliver information and regular updates to patients, and to gather annual statistics to allow for benchmarking with other European Member States.
- **PATIENT INVOLVEMENT:** Patients representatives must be invited to input, as equal partners, into conversations about strategy, funding, transparency or performance management.

Let us discuss...

1. How individual political parties can be engaged around this topic?

- Are political parties willing to include an access to medicines pledge in their upcoming election manifestos?
- Are political parties interested in raising awareness about access to medicines during political party conferences?
- Have individual TDs got the knowledge they need to tackle case work around access to medicines?

2. How the Government and its legislative bodies can be engaged around this topic?

- Would political parties be willing to include access to medicines in their Programme for Government?
- Is the Joint Oireachtas Committee on Health able to play a more proactive role in monitoring and overseeing the access to medicines processes in Ireland?

Draft text for political party election manifestos

We propose that political parties consider making a pledge to patients in their upcoming election manifestos by adopting all or some of the commitments outlined below, either with or without revision:

“In the spirit of Slaintecare, we pledge to lead on securing cross-party consensus for a sustainable solution to Ireland’s access to medicine challenges. We will establish an ongoing dialogue and partnership with patients, and families and carers of patients, to ensure that this solution is person-centered and fit-for-purpose.

We pledge to spend more and spend wiser when it comes to the National Medicine Bill to ensure that today’s patients, including rare disease patients, are guaranteed timely access new and innovative medicines with proven efficacy. We will increase the budget available for new medicines by €XXm or by XX% each year from 2020-2025.

We pledge to close the gap between European and Irish patients by committing to rank Ireland better-than-average in terms of access to medicines in Western Europe (EU-14 reference countries). We will seek to limit the time taken to reach a reimbursement decision to two years from the initial application being made by a company.”

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