

# IRELAND

## 1 in 10

adults in Ireland report they, or someone in their family, has been **unable to access medicine due to delays**<sup>1</sup>

## 84%

of adults believe it is **unacceptable** that patients in Ireland have worse access to new medicines than any other patients in Western Europe<sup>1</sup>

Patients wait an average of

## 348 days

**and in some cases, over 4 years,** for a drug to be approved for public coverage in Ireland<sup>2</sup>

## Access Restrictions in the Ireland

To make decisions about coverage and reimbursement, Ireland uses quality-adjusted life year (QALY)-based assessments conducted by the National Centre for Pharmacoeconomics (NCPE).<sup>3</sup> NCPE generally recommends that Medicines which fall below €45,000 (\$50,987) cost per QALY be reimbursed by the Health Service Executive (HSE), the Irish Department of Health, while medicines that fall above this threshold are usually not covered.<sup>4</sup> This arbitrary cost-effectiveness threshold is applied only to medicines. Additionally, due to budgetary constraints within HSE, even when drugs are approved by NCPE, patients do not automatically receive access to the treatment. These dynamics result in significant access barriers for Irish patients who are suffering from serious and complex conditions.<sup>5,6</sup>

“[Treatment is] funded by the Governments in 20 other countries in Europe, changing the lives of patients there, but not in Ireland... Time is not a luxury for Sam and the other 25 children in Ireland waiting on this drug.”

Parent of a child with Spinal Muscular Atrophy in Ireland<sup>9</sup>



Despite suffering from paralysis and pain for years, Kerri Ann, a patient with multiple sclerosis (MS) is faced with a lengthy delay before receiving treatment. Her mother, Kim, said, “We’re talking one to two years by the time a treatment plan is in place, during which time that demyelination in the brain will continue to wear away at the covers on her nerve cells – it’s more irreparable damage.”<sup>7</sup> The CEO of the Multiple Sclerosis Society of Ireland, who is working to improve access for patients, believes “**people with MS should have access to the right treatment at the right time.** This may seem like a very basic demand, and one that it would be hard to refuse, but the truth is that **this is not the situation for many people in Ireland today.**”<sup>8</sup>

<sup>1</sup> Access to Medicine Research. Empathy Research, December 2017. At <https://www.patientsdeservebetter.ie/msunderstood/>

<sup>2</sup> MS Ireland. “Patients Deserve Better.” At <https://www.patientsdeservebetter.ie/the-problem/>

<sup>3</sup> National Centre for Pharmacoeconomics (NCPE). <http://www.ncpe.ie/about/>

<sup>4</sup> Cameron D, et al. (2018). “On what basis are medical cost-effectiveness thresholds set? Clashing opinions and an absence of data: a systematic review.” *Global Health Action*, 11:1, 1

<sup>5</sup> “Irish patients denied access to drugs made in Ireland.” *The Irish Times*. September 2018.

<sup>6</sup> “‘Not fit for purpose’: How an ‘arbitrary’ system decides what drugs get funded in Ireland.” *The Journal.ie*, January 2017.

<sup>7</sup> “Kerri Ann in limbo as she faces long wait.” Belfast Media Group, August 2018.

<sup>8</sup> “MSunderstood Café in Dublin Gives Customers Glimpse into Life of MS Patients.” Multiple Sclerosis News Today, April 2018.

<sup>9</sup> Change.org petition. Available at: <https://www.change.org/p/simon-harris-oireachtas-ie-approve-new-miracle-drug-spinraza-for-sma-patients-in-ireland-immediately>.