

Time to lift the blindfold

Abolishing price secrecy to help
make medicines affordable





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Executive summary and recommendations

Over the past years, new medicines have increasingly been marketed at very high prices. This is mainly due to market imbalances in the pharmaceutical sector that favour industry over the public sector and consumers.

Before a new medicine hits a national market, there are usually price negotiations between the drug manufacturer and the national authority. However, there is currently an asymmetry of information in these talks to the disadvantage of national authorities, who must largely negotiate in the dark. For instance, governments do not know the actual costs of drug research and development.

This situation blindfolds governments and weakens their ability to set medicines prices that are fair for public health budgets and consumers. Meanwhile, the pharmaceutical industry may take advantage by charging medicines prices

well above what is needed for them to recover development costs and harvest a reasonable profit.

To get better deals during pricing negotiations, national authorities should be able to access the following information about a given medicine:

1. The price paid by other countries after any type of discount, in order to have an accurate benchmark.
2. The amount spent by companies in developing the medicine, to ensure that profit margins are reasonable and not excessive.
3. The public contribution to drug development through research funding and other incentives, to ensure that these contributions are factored into the prices paid by consumers at the pharmacy.

This publication addresses how the lack of information on relevant factors could be affecting medicines affordability. It also identifies measures that would allow the public sector's blindfold to be lifted and thereby increase its bargaining power in drug pricing negotiations.



The EU Pharmaceutical Strategy – published in November – provides momentum for setting an ambitious agenda for improved access to medicines. Shedding light on the pharmaceutical market can help in reaching that goal. Here is what decision makers at the EU and/or national levels must do on this front:

1. Facilitate the exchange of information on medicines net prices among national pricing authorities and public payers (i.e. the bodies that cover the cost of pharmaceuticals).
2. Promote the sharing of best practices among Member States on pricing policies and joint action on price negotiation and procurement.
3. Adopt measures that shed light on medicines research and development costs.
4. Ensure that patients and consumers are adequately informed about Member States' decisions around medicines pricing and reimbursement.

What is a fair price? According to BEUC, medicines prices are fair when they can be covered by public health systems and/or paid by consumers without creating an unsustainable burden. Fair prices also allow drug developers to recover their actual research and development (R&D) costs without leading to excessive profit margins. Assessing a fair price is a case-by-case exercise which could factor in other aspects such as medicines' added therapeutic value.

What about COVID-19?

The pandemic has brought the secrecy of medicine pricing into the public eye, but it is only the tip of the iceberg. The lack of transparency around the way medicine prices are set is a longstanding issue. The situation depicted in this brochure – while applicable to COVID-19 vaccines and treatments – is a source of concern for consumers and patients suffering from other illnesses and conditions.

1 Setting the scene

Medicines prices are skyrocketing

The exorbitant prices of new medicines are making headlines across Europe. A novel immunotherapy to treat blood cancer has been found to cost public hospitals in Spain €307,000 per patient.¹ At the same time, some medicines that have been on the market for a long time are undergoing huge price hikes. In several European countries, a long-existing drug used to treat gallstones became 360 to 1,000 times more expensive after being marketed as a treatment for a rare condition and the company obtained exclusive rights.²

High medicines prices put public health budgets under pressure.

As a result of high prices, public payers may decide to limit the reimbursement of medicines. This can happen even in the wealthiest countries. For example, a highly effective hepatitis C treatment was rationed due to its excessive price soon after it hit the market in countries including Belgium, Italy, Spain, Switzerland, and the United Kingdom. Lack of access to affordable treatment in Europe has led to some patients travelling to Egypt to buy pills at much lower prices.³

When governments do not reimburse medicines – or reimburse them only partially – patients and consumers bear the costs.

In some countries, including Latvia and Hungary, households have paid about half of the overall national spending on prescribed medicines from their own pockets.⁴ Out-of-pocket payments have also been particularly high in Greece.⁵ This can lead to financial hardship for consumers, and may force them to cut expenditure on other basic needs such as food and heating. Some patients are simply not able to afford the medicine they need, which can have serious implications for their health.

¹ Bernardo, A. and Laursen L., '[Spanish public hospitals pay 307,200 euros for each personalised childhood leukaemia treatment](#)', Civio Medicamentalia, 29 October 2019 (accessed 7 September 2020).

² In Belgium for example there was a price increase of 360-fold; in Italy it was 500-fold; and in Spain 1,000-fold. In Test-Achats, '[TA introduit une plainte devant l'ABC contre la firme pharmaceutique Leadiant](#)', 5 April 2019; Organización de Consumidores y Usuarios, '[OCU denuncia al laboratorio Leadiant ante la CNMC por abuso de posición dominante en el mercado](#)', 24 June 2019; Altroconsumo, '[Altroconsumo esprime soddisfazione per l'apertura dell'istruttoria Antitrust su farmaco Leadiant](#)', 15 October 2019.

³ Belmonte, E. et.al, '[4 years after the hepatitis C revolution, how much do new drugs cost?](#)', Civio Medicamentalia, 25 October 2017 (accessed 3 September 2020)

⁴ Organisation for Economic Co-operation and Development, 'Out of pocket spending: Access to care and financial protection', OECD, April 2019.

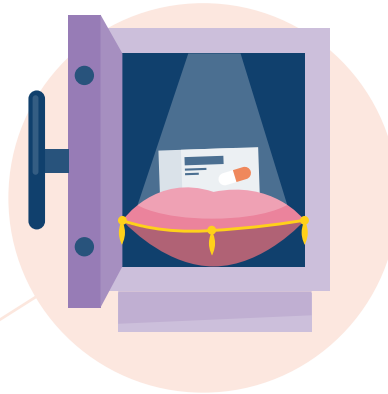
⁵ OECD and European Observatory on Health Systems and Policies, 'Greece: Country Health Profile 2019, State of Health in the EU', OECD Publishing, Paris/European Observatory on Health Systems and Policies, Brussels, 2019.

Soaring medicines prices are everyone's concern. High drug prices threaten access to treatment by those patients who need it, but that is not the only problem. High price tags for drugs also put public health budgets under pressure and may hinder the reimbursement of other health services. Setting medicines prices at reasonable levels is in the interest of society at large.



Medicines affordability is a common challenge across Europe

As mentioned above, the prices of new medicines are going through the roof. This is particularly extreme in certain therapeutic areas and for medicines dispensed at the hospital. Higher drug prices contribute to increased pharmaceutical expenditure and inequities in access.



Belgium

In 11 years, the social security system's expenditure on innovative cancer medicines increased fourfold and spending on orphan medicines increased fivefold.⁶ Data from 2018 shows that the most expensive drug of all, used to treat a rare genetic condition, cost €590,010 per patient.⁷



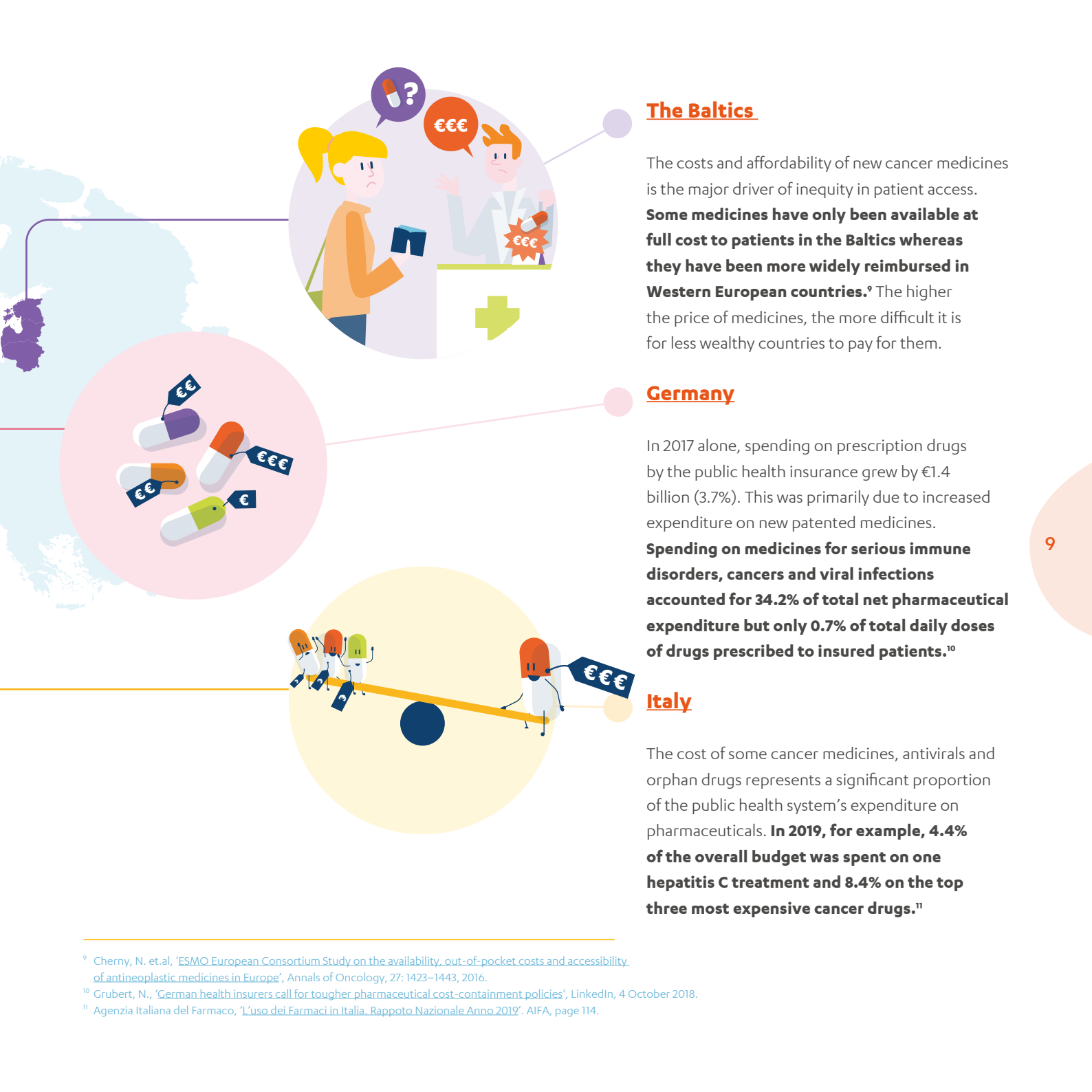
Spain

Some of the most expensive medicines are dispensed in the country's hospitals. **Both in 2018 and 2019, hospital pharmaceutical expenditure increased by nearly 8% per year.⁸**

⁶ Dokters van de Wereld, Test-Aankoop and Kom op tegen Kanker, 'Betaalbaarheid en ontwikkeling vangeneesmiddelen probemenen uitdagingen. Symposium', 8 November 2018, available [here](#)

⁷ De Wereld Morgen.be, 'Tienduizenden euro's voor één geneesmiddel: geen uitzondering', De Wereld Morgen.be, 24 October 2017 (accessed 15 October 2020).

⁸ Portal Institucional del Ministerio de Hacienda, 'Indicadores sobre gasto farmacéutico y sanitario. SERIE Gasto Farmacéutico y Sanitario: periodo Junio - 2014 a Julio - 2020', Ministerio de Hacienda, 2020 (accessed 4 December 2020).



The Baltics

The costs and affordability of new cancer medicines is the major driver of inequity in patient access.

Some medicines have only been available at full cost to patients in the Baltics whereas they have been more widely reimbursed in Western European countries.⁹ The higher the price of medicines, the more difficult it is for less wealthy countries to pay for them.

Germany

In 2017 alone, spending on prescription drugs by the public health insurance grew by €1.4 billion (3.7%). This was primarily due to increased expenditure on new patented medicines.

Spending on medicines for serious immune disorders, cancers and viral infections accounted for 34.2% of total net pharmaceutical expenditure but only 0.7% of total daily doses of drugs prescribed to insured patients.¹⁰

Italy

The cost of some cancer medicines, antivirals and orphan drugs represents a significant proportion of the public health system's expenditure on pharmaceuticals. **In 2019, for example, 4.4% of the overall budget was spent on one hepatitis C treatment and 8.4% on the top three most expensive cancer drugs.**¹¹

⁹ Cherny, N. et al, 'ESMO European Consortium Study on the availability, out-of-pocket costs and accessibility of antineoplastic medicines in Europe', *Annals of Oncology*, 27: 1423–1443, 2016.

¹⁰ Grubert, N., 'German health insurers call for tougher pharmaceutical cost-containment policies', LinkedIn, 4 October 2018.

¹¹ Agenzia Italiana del Farmaco, 'L'uso dei Farmaci in Italia. Rapporto Nazionale Anno 2019'. AIFA, page 114.

2 Barriers to fair medicines pricing: playing darts blindfolded



National authorities are currently not able to access information that could help them to set medicines prices that are fairer for public health systems, patients, and consumers. There are two reasons for this: poor transparency around medicines prices paid elsewhere, and R&D costs.

Governments are in the dark about how much other countries pay for medicines

Medicines prices are often closely regulated. This is especially important for new patented medicines for which there is no generic competition. In the EU, it is within Member States' competence to fix drug prices and to decide on their reimbursement. Although each country's system is different, there are some similarities. Generally, the maximum

¹² For example, in Spain the maximum price that a drug manufacturer can charge is set by the central government and in Italy by the national regulatory agency. Centralised pricing regulation is quite common for reimbursed drugs dispensed outside the hospital setting. Price setting for hospital medicines is more decentralised in some countries, for example in Sweden and in Austria where county councils or hospital drug committees respectively play a bigger role in this process. The Danish 'free medicines pricing system' at the pharmacy sector is quite unique. In Hungary, manufacturers are also free to determine the price of their drugs but may have to decrease the proposed price during the procedure for the inclusion of a product into reimbursement schemes. At D. Panteli et al., 'Pharmaceutical regulation in 15 European countries. Review', Health Systems in Transition, vol. 18, no.5, 2016.; and P. Kawalec et al., 'Pharmaceutical Regulation in Central and Eastern European Countries: A Current Review', Front Pharmacol. 8: 892, 2017.

¹³ Vogler, S. et al., 'Discounts and rebates granted to public payers for medicines in European countries'. Southern Med Review 5;1:38-46, 2012.

¹⁴ Morgan, SG., Vogler, S. and Wagner, AK., 'Payers' experiences with confidential pharmaceutical price discounts: A survey of public and statutory health systems in North America, Europe, and Australasia', Health Policy, 121, 354-362, 2017.

¹⁵ Agreements between pharmaceutical companies and healthcare payers that allow for the reimbursement of new medicines for which there is some uncertainty around their impact on the public budget or on their performance, and subject to certain conditions.

price that a pharmaceutical company can charge for a new medicine is set by a national pricing authority following a negotiation process.¹²

Public health systems may benefit from price reductions. The type and extent of discounts vary among countries. The most common are 'flat' discounts or rebates (refunds), followed by those linked to sales volume.^{13,14} More complex discount schemes, such as Managed Entry Agreements¹⁵ (MEAs) tied to the drug's performance, are more frequently used for new patented drugs to treat rare but serious diseases (e.g. for some types of cancer).

Price reductions are often granted directly by pharmaceutical companies on a secretive basis. Such confidentiality allows companies to claim to each payer that they are getting the best deal. An anonymous survey among payers found that confidential discounts on patented drugs usually range from between 20% and 29% off the official prices, but they can go well beyond that.¹⁶

In principle, price discounts sound like something that should benefit the public purse. But confidential discounts raise concerns:

- Within a country, certain public payers (e.g. regional health systems or health insurance providers) might end up paying more for a medicine than others for no justified reason. This can lead to inequalities in patient access.
- Countries end up using benchmark prices that are artificially higher than the amounts actually paid. This is because national pricing authorities only know the official prices set by other countries, and not the discounted prices. This creates the risk of overpaying, especially since companies first market drugs in countries that set high reference prices.¹⁷

These secret discounts mean that public payers have no guarantee that they receive the best deal according to their financial situation. In fact, countries with

lower GDPs may end up paying more for pharmaceutical products than those with higher incomes.¹⁸

In addition to not knowing the actual price of medicines, national pricing authorities also lack information about another important factor: actual research and development (R&D) costs.

The costs of drug development are opaque

It is no secret that developing a new medicine is costly. However, figures on R&D for medicines differ depending on the source. For example, a study by the industry-sponsored Tufts Center for the Study of Drug Development stated that it costs companies \$2.6 billion on average to develop a new drug (including the cost of failure and opportunity costs, i.e. what they could have earned had their money been invested elsewhere).¹⁹ The study relied on information provided confidentially by ten pharmaceutical companies.²⁰

¹⁶ See reference 14.

¹⁷ Vogler, S., V. Paris and Panteli, D., 'Ensuring access to medicines: How to redesign pricing, reimbursement and procurement?', World Health Organization, 2018.

¹⁸ Belmonte, E., 'Prices. Numbers don't fit', Civio Medicamentalia, 24 February 2017 (accessed 15 October 2020).

¹⁹ This figure includes costs of abandoned compounds, as well as opportunity costs i.e. expected returns that investors forego while a drug is in development. Without opportunity costs, it would be \$1.4 billion. At J.A. DiMasi, H.G. Grabowski and R.W.Hansen, 'Innovation in the pharmaceutical industry: New estimates of R&D costs', Journal of Health Economics, vol 47, p. 20-33, 2016.

²⁰ Love, J., 'KEI comment on the new Tufts Study on Drug Development Costs', Knowledge Ecology International, 18 November 2014 (accessed 22 October 2020).

But other stakeholders report much lower estimates. An independent study estimated that the median cost to develop a new cancer medicine among ten companies was \$757.4 million.²¹ Other estimates point to average R&D costs of \$1.3 billion when various therapeutic agents are considered.²² Both studies took into account the cost of development failure and opportunity costs.



While there is no commonly agreed method to calculate drug R&D expenditure, a major problem is that although industry claims high costs it has largely failed to disclose detailed reports on such expenditure.²³ This

lack of transparency enables companies to demand very high medicines prices and to earn royally by exaggerating the amount of money that is needed to recoup their investment. In fact, the pharmaceutical industry's high profits²⁴ indicate that lower medicines prices are possible.

What about the public contribution?

Another obstacle to fair medicines pricing is that **the pharma industry often downplays the public sector's role in drug development.** In fact, governments are major supporters of health research and the European Commission is one of the biggest funders globally.^{25,26} The EU's Research Framework Programme for 2014-2020 has a budget of €10 billion for health research and innovation.²⁷ Through this instrument, the EU supports the development of medicines and other health technologies. In 2020, this

programme received millions of extra euros to boost research into COVID-19 vaccines, diagnostics, and treatments.²⁸

While the public sector is by large the main funder of the early stages of biomedical research, which involves scientists seeking to understand how the cells and organs of the body function and what happens in the event of a disease, it also plays a role in later stages of drug development.^{29,30}

However, **public contributions are rarely reflected in studies on R&D costs, let alone medicine prices. This comes at the expense of consumers.** Even though their taxpayer contributions support drug development, consumers may still ultimately pay a high price – directly or indirectly – for these very same medicines. In short, consumers end up 'paying twice' for their medicines.

²¹ The study estimates a median cost of US\$648 million, which corresponds to US\$757.4 million for a 7% opportunity cost. In V. Prasad and S. Mailankody, 'Research and Development Spending to Bring a Single Cancer Drug to Market and Revenues After Approval', *JAMA Intern Med.*, 177(11):1569-1575, 2017.

²² Wouters, O.J., McKee, M. and Luyten, J., 'Estimated Research and Development Investment Needed to Bring a New Medicine to Market, 2009-2018', *JAMA*, 323(9):844-853, 2020.

²³ Morgan, S.G. Bathula, H. and Moon, S., 'Pricing of pharmaceuticals is becoming a major challenge for health systems', *BMJ*, 368:l4627, 2020.

²⁴ United States Government Accountability Office, 'Drug Industry. Profits, Research and Development Spending, and Merger and Acquisition Deals', GAO, page 19, 2017.

²⁵ Viergever, R.F. and Hendriks, T.C.C., 'The 10 largest public and philanthropic funders of health research in the world: what they fund and how they distribute their funds', *Health Res Policy Sys.*, 14, article no. 12, 2016.

²⁶ Vieira, M. and Moon, S., 'Research Synthesis: Public Funding of Pharmaceutical R&D', Knowledge Portal on innovation and access to medicines, 2019.

²⁷ European Commission, 'Horizon 2020. Health research and innovation funding. An investment in better health for all', 2017 (accessed 14 September 2020).

²⁸ Besides Horizon 2020 grants, the EU has helped vaccine developers to conduct clinical trials by funding the Coalition for Epidemic Preparedness Innovations and by granting them loans. Member States are also supporting the development of COVID-19 vaccines and treatments through their research funding programmes and state aid. More information on the topic in the report from Salud por Derecho, 'Public investment in R&D in COVID-19', April 2020.

²⁹ For example, a 2019 study shows that publicly supported research from around the world played a major role in the late stage discovery of at least one in four new drugs approved in the United States from 2008-2017. Many of these medicines have been authorised in Europe as well. In R.K. Nayak, J. Avorn, A. Kesselheim, 'Public sector financial support for late stage discovery of new drugs in the United States: cohort study', *BMJ*, 367:l5766, 2019.

³⁰ Pharmaceutical companies also benefit from tax credits on clinical trials. Knowledge Ecology International reports that Kymriah, a CAR-T treatment got a tax credit subsidy from the United States equal to 50 percent of the cost of qualifying clinical trials.

Medicines: consumers pay twice

Consumers help to finance drug development through their taxes. Belgian consumer group Test Achats/Test Aankoop reports that in 2015 alone, €575 million from the public administration and the EU went to biomedical research in Belgium. With this money, universities and public research centres help to develop new medicines. One example is tenofovir, a widely used HIV drug.

Tenofovir was discovered by researchers at the KU Leuven research university in collaboration with an institute from the Czech Republic. In the 1990s these researchers granted an exclusive license to the company Gilead, which developed the drug further and commercialised it. Test Achats estimates that tenofovir and its subsequent modifications provided Gilead with a revenue of €72 billion between 2008 and 2017. In the meantime, KU Leuven received about €560 million in royalties, i.e. less than 1%

of the company's turnover. During the same period, the Belgian public insurance institute INAMI spent €486 million on reimbursements for these medicines.

Besides capitalising on research carried out by the public sector, pharmaceutical companies are also the direct beneficiaries of research grants. In 2015, the industry directly received €59 million. Finally, the pharmaceutical industry also profits from generous tax incentives linked to their research activities. In 2016, the health sector benefited from €872 million in the form of tax incentives.

Reference: Test Santé: '[Médicaments. Vous les payez deux fois](#)', Test Santé, Num. 149, February 2019.



3

Lifting the blindfold: increased information sharing for fairer medicines pricing



Shedding light on R&D costs and medicines prices is crucial for improving the affordability of medicines. By addressing information asymmetries in medicines pricing negotiations, national authorities will be more empowered to set prices at levels that are fair for consumers.

This is particularly important in the case of newly developed medicines, which are more likely to put pressure on healthcare budgets and people's pockets due to their high prices. These are usually drugs for which companies have exclusive intellectual property rights - e.g. patents - that prevent competition and the ensuing lowering of prices. The recommendations below, which apply both at EU and national level, are formulated for this segment of the pharmaceutical market.

At the national level



Increased information sharing on medicines prices among public payers

- Member States should enact national legislation that enables public payers to share information on medicines net (discounted) prices between themselves. If they know that lower prices are possible, they have a higher chance getting a fair deal. A ban on binding confidentiality clauses in the pricing agreements signed with companies would be instrumental in reaching this goal.
- Medicines pricing agreements between the public and private sector should be subject to proactive scrutiny by national accounting bodies (e.g. Courts of Auditors).³¹ Governments must put in place effective mechanisms that enable patient and consumer groups to bring cases to the attention of these competent authorities.



Disclosure of research and development costs for medicines

- National legislation regulating drug pricing and decision making about reimbursement should require companies to submit detailed information on R&D costs in these processes.³²
- Pharmaceutical companies should be obliged to publicly and comprehensively report information about the public funding or incentives (e.g. tax credits) that have supported their drug development processes.
- Public funders should be required to report all funding that is awarded for biomedical research in open access, user-friendly databases. Comprehensive reporting of this information would allow for better tracking of the public sector's contribution to drug development.

³¹ In Belgium, a new law passed in April 2020 gives the Court of Auditors the right to check the agreements negotiated between the government and pharmaceutical companies, upon request by the Parliament. Prior to the adoption of this law, the Belgian KCE body which provides advice to the Ministry of Health had already called for the possibility of getting managed entry agreements evaluated by an independent body. In Federaal Kenniscentrum voor de Gezondheidszorg (KCE), '[How to improve the Belgian process for managed entry agreements?](#)', KCE, 2017.

³² Italy has made some important advances on this front by passing a decree in 2019 that mandates pharmaceutical companies to inform the pricing authority about the public contribution to the medicine's development programme. In Decreto 2 agosto 2019, 'Criteri e modalita' con cui l'Agenzia italiana del farmaco determina, mediante negoziazione, i prezzi dei farmaci rimborsati dal Servizio sanitario nazionale. (20A03810) (GU Serie Generale n.185 del 24-07-2020).

At the European level

The EU Pharmaceutical Strategy must lead to greater transparency in the pharmaceutical market. In particular, the EU should ensure:



Increased transparency of medicines net prices among EU Member States

The European Commission and Member States should respond to calls by the European Parliament and the World Health Organization for the increased transparency of medicines prices.^{33,34} This is how:

- **The EURIPID project must be supported by the next EU Health Programme.** The scope of the project should be formally expanded to enable information sharing on discounted (net) medicines prices among interested countries. This would be in line with the results of a EURIPID survey, in which most respondents (i.e. public payers) expressed interest in sharing this information.³⁵
- **Relevant information that should be shared includes data on manufacturers' prices after discounts, as well as relevant details of pricing and reimbursement agreements** including Managed Entry Agreements (MEAs).³⁶ EURIPID might need to explore specific information sharing options for those situations in which different public payers in

one country receive different discounts (a suggestion could be to report the highest and lowest net prices). The same approach could apply to medicines price discounts negotiated directly by the hospital sector.

- **The EURIPID Secretariat should continue engaging with interested parties through the Stakeholder Dialogue Platform.** It is important that EURIPID remains an independent initiative driven by participating countries. Industry should only participate via the Stakeholder Platform, which should ensure balanced participation among civil society groups.
- **Based on the experience gained with the EURIPID project, the EU should set a permanent framework for information sharing on medicines prices among Member States.** This framework should be embedded in the EU Transparency Directive (Council Directive 89/105/EEC). A revised Directive should:
 - Set up a well-resourced system that enables Member States to share information on medicines net prices and pricing agreements. At a minimum, the Directive should forbid binding clauses in pricing agreements that prevent authorities from sharing information on negotiated discounts.
 - Lay down the minimum requirements for information that pharmaceutical companies should submit to national pricing authorities, such as R&D costs.
 - Facilitate the public disclosure of medicines net prices, for example by mandating the publication of all type of discounts within a given timeframe.

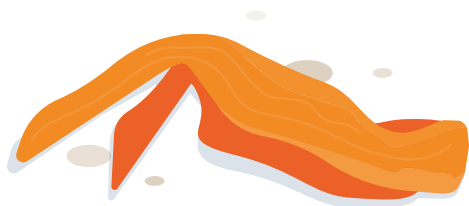
³³ European Parliament, [Resolution of 2 March 2017 on EU options for improving access to medicines](#) (2016/2057(INI)).

³⁴ World Health Assembly, [Resolution on Improving the transparency of markets for medicines, vaccines, and other health products](#), 28 May 2019.

³⁵ 14 out of 22 respondents indicated interest in sharing information with other countries on net drug prices (scope: high-cost and on-patent medicines). However, at present they are not allowed to share such information due to legal constraints and/or other boundaries. From 'EURIPID survey - Sharing information about confidential agreements', presentation given at Euripid Stakeholder Dialogue Platform, 21 September 2020.

³⁶ Where confidential agreements with pharmaceutical companies have already been signed, countries should explore possibilities for sharing -at least to some degree - information beyond the official published prices.

Going global: The benefits of greater transparency would be maximised through a level playing field at the global level. To get there, the European Commission and Member States should further advance the transparency agenda through the World Health Organization, by promoting concrete initiatives that contribute to a collective implementation of the 2019 WHO Transparency Resolution.³⁷



What is EURIPID? This is a project funded by the EU Health Programme that promotes information sharing on medicines prices. Participating countries use a common database to share information on the official (undiscounted) prices of pharmaceutical products dispensed mainly outside the hospital sector.



Stronger dialogue between Member States on pricing policies, joint price negotiations and procurement

The European Commission and Member States should promote further the exchange of information between governments on medicines pricing and reimbursement policies through a permanent network of competent authorities. They should prioritise the following:

- The advancement of discussions on the concept of ‘fair pricing’ for medicines, in line with the ongoing dialogue within the World Health Organization.³⁸
- Work on common criteria and modalities for the reporting of R&D costs by pharmaceutical companies to pricing and reimbursement authorities (e.g. types of activities and expenses that should be disclosed).
- The promotion of best practices sharing and the facilitation of cooperation on joint drug price negotiation and procurement. Such initiatives would crucially facilitate information sharing and increase governments’ bargaining power vis-à-vis the pharmaceutical industry.³⁹

Civil society must be involved in the implementation of the Pharmaceutical Strategy. The Commission should facilitate stakeholder discussion on topics related to medicines pricing, for example on the concept of ‘fair pricing’.

³⁷ See reference 34.

³⁸ Some concrete proposals have been made recently by the [International Association of Mutual Benefit Societies](#) and by S. Moon et al., in ‘[Defining the concept of fair pricing for medicines](#)’, *BMJ*, 368:l4726, 2020.

³⁹ Examples of existing initiatives are the [Beneluxa cooperation](#), under which Belgium and the Netherlands together negotiated the price of Spinraza, a treatment for spinal muscular atrophy, the [Baltic Partnership Agreement](#) for the joint procurement of vaccines such as the rotavirus vaccine, and the [Nordic Pharmaceutical Forum](#) between Denmark, Norway, Sweden and Iceland which also includes joint procurement in its scope.

4 Better public communication on medicines pricing and reimbursement

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To hold governments accountable and to increase public trust, it is essential that adequate information about medicines pricing and reimbursement is provided to the public. Patients and consumers should have easy access to information on such decisions, as they impact their access to healthcare. However, feedback from BEUC member organisations shows that:

- Countries report information on medicines prices in various formats (e.g. spreadsheets, electronic databases, online documents, etc.) and information on the various prices (manufacturer and pharmacy prices) can sometimes be published on one site or across different sites.
- It is often impossible to know whether price discount agreements have been struck.
- Published decisions on reimbursement are not always clear enough for consumers to understand.

To maximise transparency and to make information about medicines more user-friendly for consumers, governments should report the following in a centralised electronic database:

- **Pharmacy retail price** at which medicines are sold to the public before reimbursement.
- **Information on the reimbursement status of medicines**, explaining why a given medicine is reimbursed, or why not. Consumer and patient groups should be consulted for general guidance on the sets of information that are most relevant to the public, and for how to best communicate about this subject.
- **The underlying scientific evidence** upon which reimbursement decisions were made (e.g. links to summary results of clinical trials posted in official registries, layperson summary of the Health Technology Assessment report).



- **Elements of (performance-based) Managed Entry Agreements** that are relevant to patients, including:
 1. The rationale behind the agreement;
 2. details about the reimbursement scheme;
 3. how the product's performance will be measured;
 4. information on study results; and
 5. any subsequent decisions on the drug's reimbursement and the MEA's end date.Shedding light on MEAs will also facilitate independent evaluation on the extent to which these agreements have been effective in reaching their objectives.⁴⁰
- **Prices of medicines set at the manufacturer level.** In addition, governments should consider publishing information about discounted medicines prices (net prices). This is essential for accountability purposes.

⁴⁰S. Gamba, et al., argue for example that MEAs could lead to higher list prices. In '[The impact of managed entry agreements on pharmaceutical prices](#)', Health Economics, 2020.

