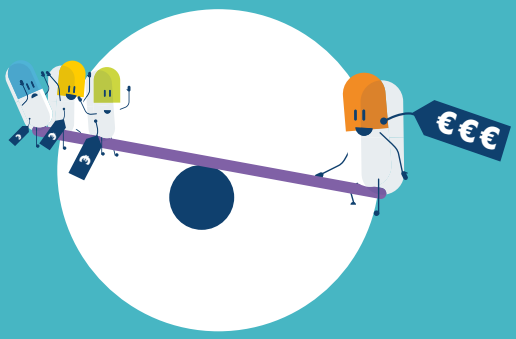
BEUC The European Consumer Organisation

WHAT CONSUMERS THINK OF MEDICINE PRICES TODAY

Results from focus groups carried out in Italy, the Netherlands and Spain



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EXECUTIVE SUMMARY

Medicines are an essential component of healthcare. They can help us stay healthy, recover from disease or live longer. But high medicine prices are putting pressure on national health budgets, requiring governments to make ever more difficult decisions about which medicines should be reimbursed by the state and which shouldn't be.

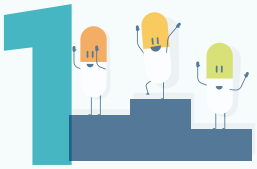
As the EU rolls out its Pharmaceutical Strategy and is preparing to review legislation, it is important that policymakers are aware of consumers' attitudes on medicine pricing. To get more data on such attitudes, BEUC commissioned focus groups in three European countries – Italy, the Netherlands and Spain. The results provide a snapshot of consumers' opinions and expectations on medicine pricing.

The findings show that healthcare is highly valued among participants and medicines considered an essential good. As a result, high drug prices and excessive profits by pharma do not sit well with consumers, and even less so when they consider the role of the public sector in medicine development.

The feedback obtained also shows that the industry is regarded as a powerful player, whilst governments hold a much weaker hand in drug pricing negotiations. The lack of real transparency in the funding of research and development (R&D) is seen as a contributing factor and something that should be fixed.

In addition, consumers regret that some medicines are not developed due to a lack of commercial interest and are puzzled by the fact that only rarely are new medicines proved to be much better than existing treatments.

SUMMARY OF MAIN ATTITUDES

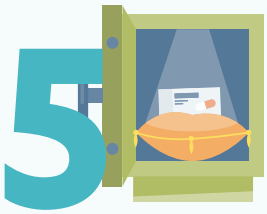


CONSUMERS HIGHLY VALUE HEALTHCARE AND CONSIDER THAT MEDICINES ARE ESSENTIAL GOODS: participants expressed appreciation for their national public health systems and the financing of services and treatments. Their attitudes on drug development and pricing show that medicines are seen as essential goods.

CONSUMERS DO NOT APPROVE OF EXCESSIVE PHARMA PROFITS, AND EVEN LESS WHEN THE PUBLIC SECTOR CONTRIBUTES TO DRUG R&D: in general, consumers did not sit comfortably knowing that companies can make huge profits out of goods as essential as medicines.

CONSUMERS THINK THE GOVERNMENT HOLDS A MUCH WEAKER HAND IN DRUG PRICE NEGOTIATIONS AND SHOULD HAVE INFORMATION ON R&D COSTS: poor transparency on research costs is seen as contributing to high medicine prices. The government cannot negotiate on an equal footing with companies without this information.

CONSUMERS THINK IT IS UNFAIR THAT SOME MEDICINES ARE NOT DEVELOPED DUE TO COMMERCIAL REASONS AND ARE SURPRISED BY THE FACT THAT NEW ISN'T ALWAYS BETTER: participants were puzzled to find out that only a few, new medicines are much better than existing treatments. They regret that drug development is not fully aligned with societal needs and neglects some diseases.



CONSUMERS THINK THERE SHOULD BE GREATER TRANSPARENCY ON DRUG R&D COSTS, GREATER RETURNS ON PUBLIC INVESTMENT AND MORE SUPRANATIONAL COLLABORATION: the results also show there is support to greater transparency on medicine prices, although some people think that knowing how much the public health system pays for a medicine could make patients feel like a 'burden'.

Bearing in mind these results, and to seize the opportunities provided by the implementation of the EU's Pharmaceutical Strategy, BEUC recommends the following:

- National governments and the EU should facilitate increased information sharing on medicines (net) prices among public payers. There should be a permanent framework for information-sharing embedded in the Transparency Directive,[1] and a requirement for companies to submit data on drug R&D costs in pricing and reimbursement processes.
- National governments should publish user-friendly information on their decisions on medicine pricing and reimbursement.
- The EU should facilitate joint procurement of medicines beyond crisis situations, for example, for high price medicines, orphan medicines and novel antibiotics.
- Funding from the EU's Horizon Europe research programme should be disbursed with access-related conditions so medicines developed with public funding are affordable.
- The Health Emergency Preparedness and Response Authority (HERA) should become an effective 'R&D coordinator' for the development of medicines for which there is little commercial interest, including novel antibiotics.
- The revision of the EU general pharmaceutical legislation should deliver a more balanced system on intellectual property incentives, facilitate timely patient access to generics and require pharmaceutical companies to generate better evidence on medicines safety and efficacy.

[1] Council Directive 89/105/EEC of 21 December 1988 relating to the transparency of measures regulating the prices of medicinal products for human use and their inclusion in the scope of national health insurance systems.

INTRODUCTION

To inform the implementation of the EU Pharmaceutical Strategy and the revision of legislation that impacts access to medicines, BEUC commissioned research on consumers' attitudes on drug pricing. We used qualitative research to get in-depth understanding on consumers' views on the topic and focused on new medicines eligible for reimbursement by the national health system.

To get a multi-country perspective, our members Altroconsumo, OCU and Consumentenbond helped us roll-out the project in Italy, Spain, and The Netherlands respectively.

The researchers used a consistent approach for the focus groups in each country with some adaptations to the national context. Consumers with diverse background took part in the focus groups between February and March 2022.

To capture more clearly the views of average users of the health system, people with specialised knowledge of the topic were excluded. Participants were not given prior information about the research which allowed capturing instant reaction opinions. During each session the research team presented a background of main topics that would drive some of the questions to participants.

More information on the methodology can be found in the annex.

STUDY FINDINGS

1 Consumers highly value healthcare and consider that medicines are essential goods

It is important to know the value people give to health and healthcare to better understand their expectations in this area. This is why this question was the starting point of the focus group discussions and became an underlying theme in the conversations.

The main takeaway is that health is highly valued, and healthcare largely considered a matter of public interest. Participants see medicines as essential and distinctive goods.

Discussion

During the sessions people shared their views on health from an individual and structural perspective. At an individual level, there were allusions to health as an important factor in life that is sometimes given for granted until one is at risk of having their health damaged or you reach a certain age.

> *"It is an important conditioning factor for your life in general. You can have a lot of money, you can have a great job, but if you are very "poorly", it is of no use to you." Spain*
>
> *"For me, health is a given until you lose it and only then you see how important it is." The Netherlands*

From a structural point of view, healthcare is largely considered a matter of public interest. Participants showed appreciation for their national health system and the financing of services and treatments and compared it to the situation in other countries, mainly the United States.

> *"Public healthcare is also very important. I don't want to get involved in politics, but the important thing is that healthcare should be public, because private healthcare can only be paid for by a few people, no more. The rest of us, ordinary people, cannot afford to pay for private care. So, there must be a good public health system." Spain*
>
> *"I have to take medicines... I had a heart attack (...) some are even quite expensive... the therapy is reimbursed by the health service... so that is ok with me. All in all, our health service, compared to certain other situations abroad is better, that's it." Italy*
>
> *"Healthcare in the Netherlands is very good if you compare it to the US... a friend of mine had to pay 500 dollars the other day for a medicine." The Netherlands*

At the same time, in all countries, participants mentioned aspects of their national health system that need improvement. For example, in Italy and Spain there were complaints about long waiting lists, whilst in the Netherlands some participants argued that the mandatory "excess"[2] citizens have to pay is too high and a barrier for certain people. During these discussions, some participants called for investing more in healthcare.

> *"Regarding the health service, it is a pearl that must be preserved, and unfortunately it has been mistreated for many years here - for many years. I say that we need to invest more." Italy*
>
> *"Instead of subsidising highways and freeways and all these things, they could be used for this [health], it is more important." Spain*

In relation to medicines, people's opinions expressed during the sessions show that they generally considered them essential goods. So much so that some participants referred to medicines as being so vital that patients and health systems might end up paying a high price if there is no other alternative. This signals that when it comes to medicines, people see the end-buyer as 'vulnerable'.

> *"People depend on certain medication, so you can ask whatever you want for it. We will pay for it." The Netherlands*
>
> *"We're not talking about buying a pair of trousers. (...) the stakes are to buy a medicine, something that we are in need of." Spain*
>
> *"We are talking about life-saving [cancer] medicines... why [call it a] "market"? I can sell cigarettes to anyone who wants to smoke, wants to hurt themselves, and I can sell any other stuff, but let's find ... a different word for medicines, that's it. Medicines should be distributed for free." Italy*
>
> *"What happens is that capitalism applied to medicines perhaps is not the most ethical thing to do" Spain*

[2] Maximum amount of money that citizens who are 18 or older have to pay annually for the health services covered by the public health system, in addition to the insurance premium. In 2022 the ceiling of the "excess" was fixed at €385 euros. For some types of care, such as consultation with a general practitioner, patients do not have to pay these fees.

2 Consumers do not approve of excessive pharma profits, and even less when the public sector contributes to drug R&D

Many people take medicines but not everyone might know that pharmaceutical innovation is usually the result of a lengthy, collective, and cumulative effort by both the public and private sectors. Yet, whilst taxpayers help finance this process, companies end up making billions of euros in sales out of medicines every year.[3]

The focus groups show that knowledge on drug R&D is fairly limited among average citizens, and this means there is a tendency to underestimate the role of the public sector. However, when people think about it, they tend to see there should be greater return on public on investment.

Another takeaway is that it does not feel right to many participants that companies make huge profits out of medicines, and even less so if the public sector contributes to their development. During the discussions, participants made connections between high profits, drug prices, and affordability.

Discussion

In all countries there was limited knowledge on how exactly the R&D process works. Some participants expressed uncertainty about the functioning of the system, whilst others had a basic idea about it that was more or less accurate.

For example, in Spain participants portrayed the development process as being 'complex', 'long' and 'expensive' and could guess the phases it comprises. They argued it must be more cumbersome than in other sectors because of the need to ensure safety guarantees. However, participants tended to underestimate the role of the public sector in health research. When they were made aware of it, many were surprised.[4]

> *"What strikes me...is that in the end we are paying for it ourselves. Because if it starts to be financed..., research into a drug, it starts in the public sphere, charged to the state budget. Who pays the state budget? Well, all Spaniards with our taxes. (...) So, it is even more blatant that they charge you for a drug, when in the end it is you, with your taxes, who is making sure that this can be researched, or at least at the beginning." Spain*

[3] Just in 2021, the bestselling medicine worldwide was a COVID-19 vaccine which reported sales of $36.8 billion, and the last amongst the top 20 was a cancer treatment with sales worth $5.4 billion. In Dunleavy, K. (2022, May 31). The top 20 drugs by worldwide sales in 2021. *Fierce Pharma*.

[4] OECD data shows that in 2014, in Spain the public sector and non-profits financed 62% of the expenditure on health-related research, and the private sector 38%. The OECD also reports that in 2018, governments in Europe for which data was available spent $16 billion collectively in health-related R&D. This figure understates total government support since it excludes most tax incentives and spending by public corporations or general university funding that is subsequently allocated to health. In the same year, the pharma industry spent $23.7 billion on R&D across the same countries. See: OECD (2021). Health at a Glance 2021: OECD Indicators, OECD Publishing, Paris.

In Italy the majority of participants were unsure about who usually finances drug R&D. Some said pharmaceutical companies, while others argued that it was done with the support of public entities. Among these claims, a few mentioned the example of COVID-19 vaccine development which has been highly subsidised by governments.

Similarly, in the Netherlands there was little awareness about the entire 'journey' of a medicine until it is available to patients. Whilst participants were not surprised by the fact that governments help finance drug development, they had some prospects on medicine prices reflecting that contribution. This came up when discussing the case of Sovaldi, a drug to treat hepatitis C.

SOVALDI CASE

Sovaldi (sofosbuvir) is a highly effective treatment for hepatitis C, with cure rates greater than 90%. The medicine was developed by researchers from Emory University in the United States who eventually founded a small company (Pharmasset). The U.S. National Institutes of Health supported with $61 million research projects that contributed to the development of sofosbuvir.[5]

With such a promising medicine at hand, Pharmasset soon became of interest to Big Pharma. So much so that in 2011 Gilead bought it for $11.2 billion, whilst Pharmasset spent $271 million from 2003-2011 in R&D.[6]

Gilead carried out the last stage of clinical trial development for sofosbuvir and received a marketing authorisation in 2014, following the European Medicines Agency's positive opinion. In the early years, the price for a 3-month treatment in Spain, Italy and the Netherlands ranged between €25,000-€55,000. At those prices, several European countries rationed patients' access to the treatment whilst Gilead made $10.3 billion in sales globally just in the first year.[7]

A 2014 study estimated that production for a 3-month course with sofosbuvir could range between $68–$136.[8]

When they learned about this case, Dutch participants could not understand that a product developed with public funding can cost so much. Whilst they thought that the acquisition costs paid for by big pharma were a possible explanation for the medicine's high price, it did not make the situation acceptable.

> *"This is one big money machine. We pay taxes and also pay the high costs for medication. Sounds wrong." The Netherlands*

In the Spanish focus groups people were also surprised with the high price of Sovaldi when they compared it with the low production costs. Several people argued that it is important to know if companies benefited from public funding when developing the medicine. The rationale is that it should be reflected in its price, especially if the contribution is considerable.

> "That difference is not normal." Spain
> "Shameful, honestly." Spain
> "But how did you obtain that pill? With what money, with what aid, with what subsidies?" Spain

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5 Barenie, RE. et al., (2021). Public funding for transformative drugs: the case of sofosbuvir. *Drug Discovery Today*, Volume 26, Number 1.

6 Includes expenditure on sofosbuvir and other failed compounds. In Roy, V., King. L. (2016). Betting on hepatitis C: how financial speculation in drug development influences access to medicines. BMJ, 354:i3718 doi: 10.1136/bmj.i3718

7 Pollack, A. (2015, February 3). Sales of Sovaldi, new Gilead hepatitis C drug, soar to $10.3 billion. The New York Times

8 Hill, A. et al., (2014). Minimum Costs for Producing Hepatitis C Direct-Acting Antivirals for Use in Large-Scale Treatment Access Programs in Developing Countries. *Clinical Infectious Diseases*, Volume 58, Issue 7

In Italy, some participants wondered if there are some conditions or returns for governments which help finance drug development. When discussing the Sovaldi case, many participants were critical about the company's high profits and called for limiting them.

> *"If public entities fund [research], do they have access to confidential information from the private pharmaceutical company [on R&D costs] or do they simply pay but have no return, no feedback?" Italy*
>
> *"Talking about the percentage of earnings when the public intervenes in financing research and development, the percentage has to be decided immediately ... not 50 times as much but fixed at three times as much." Italy*

A common attitude in all surveyed countries is that people realise that developing new medicines is costly, but it doesn't feel right that pharma companies can make excessive profits from medicines. A zoom into the focus group discussions showed that:

- Pharma is seen by many to make too much money out of some drugs, especially when estimates on R&D costs are compared with revenues,[9] which did not feel right to participants.
- Some stress that they could accept a certain level of (high) profit if it guaranteed that those benefits will be reinvested into more research.
- People made connections between high profits, drug prices and affordability.
- Often, attitudes towards pharma's profits stemmed from people's idea that health is not 'regular business' and medicines are not like other type of goods.
- There were expectations on getting some return on public investment when the public sector contributed to drug R&D.

[9] Prasad, V., Mailankody, S (2017). Research and Development Spending to Bring a Single Cancer Drug to Market and Revenues After Approval, *JAMA Intern Med.*, 177(11):1569-1575, 2017

Views on the topic in participants' own words:

"Today, unfortunately, even health is money. Well, it's a shame, it's a shame." Spain

"Those profit margins should not be allowed. That's it, period." Spain

"Obviously it is a company, and it has to make a profit, but they are supposed to do it to help. So, there should be a balance between, what you earn because you've worked hard, but you can't set it [the level of profit] at, I don't know, 300%." Spain

"If it is the case that most of it [medicines] goes through the public sector, pharmaceutical companies should also make an effort to set more affordable prices, not take so much." Spain

"Pharma is a money machine, they profit from a society that is ill." The Netherlands

"These costs might also affect our health insurance, if the [medicine] prices were lower the costs for the insurance might be lower." The Netherlands

"More medication has to be developed, this costs a lot." The Netherlands

"It is not the individual who pays for these medicines, but the state. If the individual had to pay all the cancer therapy, there would probably be a popular uprising in Italy. (...) In my opinion the pharmaceutical companies can perhaps afford such high revenues because the cost of these therapies does not fall on the shoulders of the individual, but it is shared among everyone, and we all say nothing." Italy

"I do not know in how many other sectors of the economy or production there are margins like those and that is quite sad because, in any case, this is money on the health of citizens and public money... I don't know, maybe we need to review the roles of patents... It is impressive. (...) I am completely liberal, that is, I am completely for the free market, but I am not for the free market in certain sectors, such as the pharmaceutical one which has an impact on the life and health of citizens and on the finances of the State." Italy

3 Consumers think their government holds a much weaker hand in drug price negotiations and should have information on R&D costs

Pharma companies argue that medicine prices are high because R&D costs are high. However, they are reluctant to disclose detailed reports on the amount they invest in each of their products. R&D costs estimates vary greatly, with studies that have closer links to the industry reporting much higher figures than more independent studies.

The focus groups discussed the question of R&D costs, and the findings show that there is support for greater transparency on these costs. Some participants felt stronger on this question when they considered the public sector contribution to drug development.

R&D costs are seen as important information that governments should have at their disposal to be able to negotiate better. Not having this information puts governments in a disadvantaged position vis-à-vis the pharma industry, which is seen as a more powerful player.

Discussion on R&D cost transparency

To kick off discussions on the cost of developing medicines, participants in all countries were invited to comment on different estimates regarding R&D costs of medicines.

One of the figures was from a study by the industry-sponsored Tufts Center for the Study of Drug Development which found it costs companies about $2.6 billion on average to develop a new drug (including cost of failure and opportunity costs).[10] The study relied on information provided confidentially by ten pharmaceutical companies.

In addition, participants saw figures from an independent study which estimated that the median cost to develop a new cancer medicine among ten companies was $757.4 million,[11] and another one which points to average R&D costs of $1.3 billion when various therapeutic agents are considered.[12] These two other studies also took into account the cost of development failure and opportunity costs.

In the Netherlands, participants found the figures to be so high but, at the same time, were puzzled to see they are so diverse. Some wondered if companies presented higher figures on research costs so they can set higher prices for medicines.

> *"Pharma companies present the highest figures, they are the closest source so it might be true. But maybe it is also to lessen their sense of guilt [over high drug prices]. It is just big business." The Netherlands*
>
> *"They [the industry] just present the costs as very high so we are willing to pay a lot for medication." The Netherlands*

Participants in Italy were also very surprised by the high figures of the R&D costs. Those who compared the estimates by source were split in their positions. Some said that companies exaggerated R&D costs to justify high drug prices; others that the researchers using confidential data from pharma companies present higher estimates because they have more information.

> *"I would not discard the higher estimate immediately ...anyway they are researchers... the fact of being linked to pharmaceutical companies may also have a positive aspect, in the sense that you could know the dynamics better and therefore could have a clearer idea of the costs. One could imagine that there may be an interest in pushing up the production costs to justify the costs also of distributing the medicine. But (....) I should think a voice closer to the company is able to get more information... even if, actually, they are all very large amounts." Italy*
>
> *"The cost is very high ... I am very surprised here too ... I knew it was high, but (...) the first estimate [highest figure] is linked to companies, every company tends to say that it has spent more, ...also to reduce its taxes (...) I would only take these two [lower figures], but precisely because they come from independent researchers and in my opinion, this is fundamental in this field." Italy*

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10 DiMasi, JA., Grabowski HG., Hansen, RW (2016). Innovation in the pharmaceutical industry: New estimates of R&D costs, *Journal of Health Economics*, vol 47, p. 20-33, 2016.

11 Prasad, V., Mailankody, S (2017). Research and Development Spending to Bring a Single Cancer Drug to Market and Revenues After Approval, *JAMA Intern Med.*, 177(11):1569-1575, 2017

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

Information on different R&D cost estimates provided the basis in all countries for subsequent discussions on transparency. Among participants, there was criticism of the lack of real transparency on R&D costs and support for shedding light on this data as well as on production costs. Some people had stronger positions on the question of transparency when they considered the public sector contribution to drug development. The findings show that data on R&D costs is seen as important information the government should have in price negotiations, otherwise it is in a disadvantaged position.

> *"The problem that they [companies] do not have transparency in the production price [cost] or what the development is costing them, also influences the price that they can set for the product. If I inflate the price of development and research as much as I want, even if it has cost me 4 dollars, then, in the end, the price of the product can also be inflated. Because if I tell you that it cost me four dollars, I can't ask you for a million dollars for the product." Spain*
>
> *"That is weird that the government does not know what the R&D costs are. This way they [companies] can ask any price they want." The Netherlands*
>
> *"If it has been financed with public funds, you have to know how much it costs to produce it." Spain*
>
> *"I think it [R&D costs] should be public, all public." Italy*
>
> *"We can gain on the [transparency of] development costs, they are in no relation to the price now." The Netherlands*

The notion that governments need to be empowered in drug price negotiations stems from the fact the pharma industry is seen as a very powerful player, which has something that society needs. To balance the system, some participants propose that governments team up.

> *"What can we do, they [companies] are more powerful." The Netherlands*
>
> *"Why don't countries join forces to buy a drug all together so that the price is cheaper? For example. If each one does it separately, the price will be more expensive than if they do it together, right?" Spain*

Discussion on medicines' price transparency

In addition to R&D cost transparency, the focus groups also touched briefly on the question of information on medicines' prices. This topic was approached slightly differently in the three countries.

In the Netherlands, where the focus was the lack of transparency on net prices paid by other countries, some argued that this situation weakens the government's hand in its negotiations with pharma companies.

> *"It is crazy the government does not have information on the R&D costs and on what other countries pay for a certain medicine." The Netherlands*

In Spain, the discussions focused on citizens' access to information. Some participants said they felt uninformed about which criteria the government follows to decide which medicines are publicly financed and which are not. There was also interest in knowing how much the public administration pays exactly for each medicine.

In Italy, two main positions arose. On the one hand, some participants argued that full transparency in this area is necessary for public accountability. At the same time, in one of the sessions, a person mentioned that knowing how much the public health system pays for a medicine can make some patients feel guilty, as if they were a 'burden', and some participants expressed their agreement on this topic.

> *"If a price is confidential, the reason is that you don't want the public to know the price. (..) I would say that personally I do not feel comfortable about pricing being confidential, because a relationship between the private company and the public administration should be transparent. It perplexes me. If they were two private companies, they could do what they want. The fact is that public money is used for a confidential price. I swear I did not know this, and it worries me a lot." Italy*
>
> *"... as citizen with a problem (...) I already have my mental fragility - even the idea that I have a "cost". Some difficult psychological dynamics can emerge. Not only on the patient who discovers this, but also on anything that can trigger public opinion (...). As a sort of compromise, it [medicine cost] should only be requested by certain entities, but certainly not available to everyone. I don't want it." Italy*

4 Consumers think it is unfair that some medicines are not developed because of commercial reasons, and are surprised by the fact that new isn't always better

Over the years there have been important medical advances in some areas, but some diseases have received less research than others. In addition, new medicines are not always better than what is already available. These two questions were also addressed by the focus groups.

Participants consider it unfair that there is little research into medicines that treat certain diseases just because the industry considers these medicines would be less profitable. They were also surprised to see that few, new medicines are proved to be considerably better than the treatment already available.

Discussion

All participants were invited to comment on data showing the type of medicines per therapeutic area that are the most and the least researched and/or marketed.[13] [14]

In general, they do not find the situation acceptable from a societal perspective and think that the market-driven model of drug development leads to situations of unfairness.

> *"In my opinion, the criterion is just to sell, and that's it, so a lot is played on... let's say the pathologies that are spread globally, while for rare diseases or diseases that affect very few people, investments are laughable, and some drugs are even no longer produced." Italy*
>
> *"Business-wise I understand their decision, but it is sad that when you have a rare disease, they will not develop a medicine for that." The Netherlands*
>
> *"I think that these big pharmaceutical companies should be obliged to invest a percentage of their profits in research for all these diseases that have no cure or that have no medicine." Spain*

In addition to discussing drug development choices, participants were also invited to react on ratings about medicines' clinical added value. In all countries, people were surprised and even puzzled to know that an independent analysis found that only 8% of 109 medicines approved mainly at EU level, and rated in 2020, were considerably better than existing treatments. This means that only 9 out of 109 drugs approved were much better than what was already available, whilst another 18 drugs represented a little advance for patients and 55 offered nothing new.[15]

> *"Honestly, I was a bit perplexed, because I thought that research always tended to develop medicines that were more advantageous than the previous ones (...) I am really very negatively surprised." Italy*

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13 Pedrique, B. et. al., (2013). The drug and vaccine landscape for neglected diseases (2000–11): a systematic assessment. *Lancet Glob Health*, 1: e371–79

14 World Health Organization. (2018). Pricing of cancer medicines and its impacts. Geneva: World Health Organization; Licence: CC BY-NC-SA 3.0 IGO.

15 Another 10 drugs were found to be worse than existing treatment and to bring more risks than benefits, and there was reserved judgement for 17 products due to insufficient data when the assessment was performed. In Prescrire (2021). Drugs in 2020: a brief review, Prescrire International, 30 (225): 108-109.

CONCLUSIONS AND POLICY RECOMMENDATIONS

The focus group results show that in general consumers see medicines as essential goods that should not be regulated by common market dynamics. They also had little knowledge about the pricing, reimbursement and R&D mechanisms in place and the way the public sector helps fund the development of medicines. We are able to draw the following conclusions from what they said. They expected:

- Strong regulation in the area of healthcare and pharmaceuticals.
- Greater transparency on R&D costs.
- Public return on public investment, for example by reflecting the public contribution to drug development in medicines' prices.
- New medicines bringing added therapeutic value.
- Supranational structures and collaboration on drug pricing, to overcome the perceived asymmetry of power between governments and the pharma industry

The research findings are an indication of trends, which is in itself relevant to get policymakers reflect on the matter at time of important policy developments at EU level.

Keeping these results in mind while the EU rolls out the Pharmaceutical Strategy for Europe and plans to revise important legislation on medicines, BEUC calls for introducing the following policy changes at the national and EU levels.

At the national level

1 FACILITATE INCREASED INFORMATION SHARING ON MEDICINES PRICES AMONG PUBLIC PAYERS

- Member States should pass national legislation that enables public payers to share with one another information on the net (discounted) prices they pay for medicines: more transparency will increase the likelihood of governments getting a fair deal when they negotiate drug prices with the industry, as they might realise that lower prices are possible.
- Medicine pricing agreements between the public and private sector should be subject to proactive scrutiny by national accounting bodies (e.g., courts of auditors). This will enhance accountability on these negotiations and increase public trust.

2 MANDATE DISCLOSURE OF RESEARCH AND DEVELOPMENT COSTS FOR MEDICINES

- Laws regulating drug pricing and reimbursement should require companies to submit detailed information on R&D costs in these processes: this will help address information asymmetries in governments' negotiations with the industry.
- Pharma companies should be fully transparent about any public funding or incentives (e.g., tax credits) that have supported their drug development efforts: this will help factor these contributions into medicines' prices.[16]

3 ENSURE THAT THERE IS EASY AND COMPREHENSIVE ACCESS TO INFORMATION ON DECISIONS RELATED TO DRUG PRICING AND REIMBURSEMENT FOR PUBLIC ACCOUNTABILITY

- All Member States should report in a centralised public database their decisions on medicine pricing and reimbursement and include the sets of information that are most relevant to consumers. Governments should consider publishing information about medicine net prices to strengthen public trust and accountability.

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[16] Italy 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. However, the Decree does not require companies to disclose their own R&D costs.

At European level

1 PROMOTE MORE COLLABORATION ON MEDICINE PRICING

- The European Commission should promote further collaboration between Member States on medicine pricing and reimbursement and facilitate joint procurement of medicines beyond crisis situations, for example, for high price medicines, orphan medicines and novel antibiotics.
- The EU should set a permanent framework for information sharing on medicines (net) prices among Member States. This framework should be embedded in the EU Transparency Directive (Council Directive 89/105/EEC). To empower national governments across the EU, the revised Directive should require that pharma companies submit data on R&D costs in drug pricing negotiations.

2 ENSURE THERE IS GREATER RETURN ON PUBLIC INVESTMENT

- The European Commission should attach access-related conditions when funding from Horizon Europe is disbursed to support biomedical research.
- HERA must become an effective 'R&D coordinator' for the development of medicines for which there is little commercial interest, including novel antibiotics.

3 INTRODUCE MEASURES FOR IMPROVED MEDICINE AFFORDABILITY IN THE GENERAL PHARMACEUTICAL LEGISLATION

- Outline different periods of data and market protection depending on whether the medicine meets unmet medical needs or not, in order to channel innovation where it is most needed.
- Introduce safeguards in the data and market protection regime that help prevent excessive prices and profits, based on the transparency of R&D costs.
- Allow waiving data and market protection in case Member States trigger compulsory licensing.
- Introduce measures that enable timely patient access to cheaper generics and biosimilars.
- Require companies to submit to medicines agencies evidence from randomised controlled clinical trials that compare the medicine versus standard treatment, unless when exceptionally justified.

For more information on barriers to medicines' fair pricing, see BEUC publication
'Time to lift the blindfold: Abolishing price secrecy to help make medicines affordable'

Table 1 - Summary of methodology

	ITALY	NETHERLANDS	SPAIN
TARGET	General population	General population	General population
NUMBER OF PARTICIPANTS	17	20	18
AGE RANGE	28-73 years old	34-64 years old	28-71 years old
GENDER	65% female; 35% male	50% female; 50% male	50% female; 50% male
HEALTH STATUS*	Most participants used medicines periodically to treat chronic conditions or diseases (e.g., hypertension, hypercholesterolemia, cancer, panic attacks).	Over half of the participants (11) are chronically ill and take medication for their illness	The recruitment of participants was guided by the age variable, which is a proxy for chronic medication use.
MINIMUM EDUCATIONAL LEVEL	All had completed at least compulsory school	All had finished at least secondary education at medium level	All had completed at least compulsory (secondary) education, except for 2 participants who had only primary studies
RECRUITMENT PROCESS	Convenience network of people (e.g., contacts of contacts)	Recruiting agency	Recruiting agency
SESSIONS	Four groups; four to five participants each Duration: around 2h 30' each	Four groups with five participants each Duration: 2 hours each session	Three groups with six participants each Duration: Between 1h 45' and 2h 15'
MODALITY	Online **	Online **	Physical
EXCLUSION CRITERIA	People with specialised knowledge such as healthcare workers, pharma and medical device industry employees, researchers, or medicines policy board members.	People with specialised knowledge, such as those working in health services or the pharma industry, researchers or people working in medicines policy. In addition to journalists, communication professionals, politicians, medical personal and market researchers.	People with specialised knowledge, such as workers in the healthcare sector or the pharmaceutical industry, researchers or people involved in medicines policy
RESEARCH TEAM	Istituto di Richerche Farmacologiche Mario Negri – IRCCS	STiPT The public health NGO Wemos helped translate and adapt the focus groups materials to the local setting	APLICA coop.

* Participant's health status was either asked about during the recruitment process (the Netherlands) or inferred from statements made by participants during the sessions (Italy). In Italy, age was also used during the recruitment process as a proxy for chronic medication use.

** The COVID-19 situation in the country was one of the factors that researchers considered when choosing the modality of the sessions.

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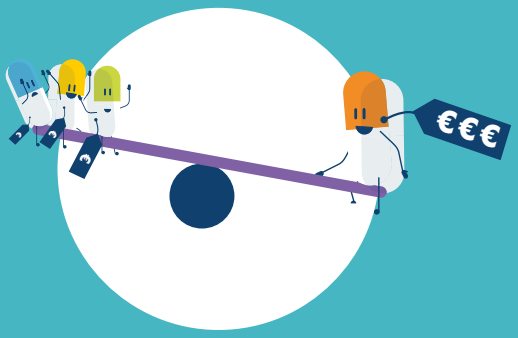

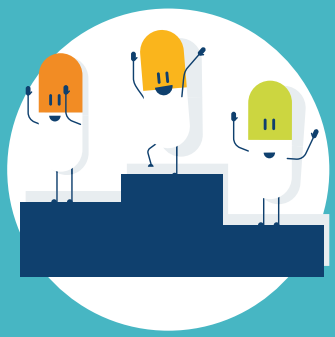

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