

WHO PAYS, WHO BENEFITS — AND WHO KNOWS?

TRANSPARENCY, PUBLIC
CONTRIBUTIONS, AND ACCESS TO
MEDICINES



EXECUTIVE SUMMARY

Public funding underpins a far larger share of pharmaceutical innovation than is commonly acknowledged. From basic research and clinical trials to regulatory support and post-market evidence generation, public actors contribute at every stage of the drug development lifecycle. Yet these contributions remain largely invisible in pricing negotiations, access conditionalities, and public debate. Meanwhile, medicines continue to be priced as though innovation is exclusively a private-sector endeavour.

This policy brief distils the key insights from the webinar 'Who Pays, Who Benefits — and Who Knows? Transparency, Public Contributions, and Access to Medicines' (Transparency Series 2×02, February 2026). Drawing on expert presentations and discussion, it examines how public contributions to pharmaceutical R&D can be identified and mapped; why the lack of transparency around R&D costs creates a structural imbalance in price negotiations; and what the case of the MVA-BN Mpox vaccine illustrates about the gap between public investment and public benefit.

About the webinar

This report is based on the Transparency Series webinar 'Who Pays, Who Benefits — and Who Knows?' (February 2026), featuring contributions from:

- Claudia Wild (Austrian Institute for Health Technology Assessment – AIHTA, ret.; Transparency International Healthcare)
- Roz Scourse (Médecins Sans Frontières – MSF)
- Megan Whiteman (Public Citizen – Access to Medicine Program)

The webinar was moderated by Jaime Manzano and Adrián Alonso (Salud por Derecho).

1. PUBLIC CONTRIBUTIONS TO PHARMACEUTICAL R&D: A SYSTEMATIC GAP

A central theme of the webinar was the scale and systematic underrecognition of public contributions across the pharmaceutical innovation lifecycle. Far from being limited to early-stage basic research, public funding flows through every phase of drug development — from foundational science to clinical trials, regulatory approval, and post-market evidence generation.

Claudia Wild presented findings from the HI-PRIX project, a European Commission-funded research initiative that developed a framework for identifying and categorising public contributions across eight development phases. This framework challenges the prevailing narrative that innovation is primarily a private-sector achievement — a narrative that has long been used to justify high medicine prices and resist access conditionalities.

THE EIGHT PHASES OF PUBLIC CONTRIBUTION

The HI-PRIX framework maps public support across the full development cycle:

- Basic and translational research — funded by national, supranational, and international science institutions.
- Pre-competitive applied research — supported through public-private partnerships such as IMI/IHI at EU level.
- Preclinical research — enabled through technology transfer grants for academic spin-offs and biotech start-ups.
- Innovation and regional economic support — including tax breaks, infrastructure provision, and cluster subsidies.
- Clinical research infrastructure — direct and indirect public funding, including access to patient populations in specialised centres.
- Clinical development — public co-funding of Phase 1–3 trials.
- Regulatory support — scientific advice, fast-track designations (orphan, PRIME, ATMP), and tax credits.
- Post-market evidence generation — public registries and real-world evidence networks built for industry benefit.

The literature reviewed as part of the project — based predominantly on FDA-approved drugs — found that public-sector institutions contributed to approximately 42–50% of all biologicals and over 90% of drug target research. For products receiving 'priority' or 'expedited' review — those deemed most therapeutically important — public contributions were identified in 64–68% of cases.

In Europe, 12.3% of all Framework Programme 7 health research awards funded late-stage clinical development, with pharmaceutical products and vaccines accounting for 84% of those awards.

Wild also presented a company-level analysis covering all products approved by Novartis and Novo Nordisk between 2014 and 2024. Of Novartis's 25 products approved over that decade, 16 — or 64% — had been acquired, licensed, or co-developed in ways that traced back to publicly funded research. This directly challenges industry claims that high prices are necessary to recoup private R&D investment.

"We have to critically examine the narrative and myths that only private companies are the innovators in this world. The public sector gives the infrastructure — economic and regulatory — on which private actors can live. But that means fair prices thereafter, and not only prices that give benefits to the private companies."

Claudia Wild, Austrian Institute for Health Technology Assessment (ret.) / Transparency International Healthcare

The Austrian appraisal board for high-cost medicines — including gene therapies, ATMPs, and oncology drugs — now includes a dedicated chapter on identifying public contributions for each product under review. Wild presented case analyses showing that even at late stages of development, public funding was often substantial, sometimes exceeding private investment for specific products.

WHAT ARTICLE 57 DEMANDS — AND WHAT IT STILL NEEDS

A key policy anchor for the discussion was Article 57 of the negotiated EU Pharmaceutical Directive, which introduces a legal obligation for marketing authorisation holders to declare any public financial support received during the development of their products. This represents a significant step forward, but as Wild argued, implementation will determine whether it is transformative or symbolic.

The HI-PRIX project produced a freely available guidance document outlining how such searches can be conducted and standardised. Key policy actions proposed to give Article 57 real effect include:

- Uniform, transparent reporting of all public contributions across R&D and innovation support — including national, regional, and start-up funding that currently escapes disclosure.
- Transparent reporting of IP transfers, licensing agreements, and mergers and acquisitions that carry publicly funded knowledge into private ownership.

- Development of contractual options — including fair price clauses, non-exclusive licensing, patent pooling, and profit-sharing thresholds — to ensure public benefit from publicly funded discoveries.
- Binding requirements for industry R&D expenditure reporting, with clear criteria excluding spending that currently inflates declared R&D costs, such as seeding trials and marketing activities.
- EMA control systems with effective sanctions — including the power to halt approval procedures — for non-compliance with disclosure obligations.
- Learning communities of procurers and pricing authorities to share methodologies and build collective negotiating power.
- Revitalisation of public infrastructure for drug development and approval, to demonstrate that public actors can function as innovators across the full value chain — not merely as funders of private profit.

A particular concern raised during the webinar is the opacity surrounding national and regional innovation funding — cluster grants, SME support, and location subsidies — which is structurally harder to trace and has received far less attention than EU-level or US federal funding.

2. R&D COST TRANSPARENCY: AN EVIDENCE-FREE ZONE

If public contributions represent one side of an information asymmetry in pharmaceutical pricing, R&D cost opacity represents the other. Roz Scourse of MSF's Access Campaign presented work focused on why the lack of transparency around actual R&D costs creates a structural barrier to evidence-based policy and equitable pricing negotiations.

Despite frequent industry claims that high prices are necessary to recoup costly R&D investment, there is almost no actual published data on what specific medicines cost to develop. What exists are estimates and averages with an extraordinary range: full R&D costs for a new drug range from US\$43.4 million to US\$4.2 billion depending on methodology — a 100-fold spread. For Phase 2–3 clinical trials alone, estimates range from US\$5 million to US\$142 million. As Scourse noted, R&D costs are effectively an 'evidence-free zone'.

This opacity has concrete consequences: it is cited as a justification for high prices without any supporting evidence; it prevents the design of well-calibrated financial incentives for areas of unmet need such as antimicrobial resistance or pandemic preparedness; and it undermines accountability for public investment — since without knowing what R&D actually cost, there is no basis for evaluating whether public support is delivering fair returns.

FROM PRINCIPLE TO PRACTICE: THE TB-PRACTECAL CASE

Rather than simply advocating for transparency, MSF chose to apply it to itself. Following its adoption of a clinical trial transparency policy in 2022, MSF conducted a retrospective cost analysis of TB-PRACTECAL — a large Phase 2b-3 adaptive trial testing shorter, all-oral regimens for drug-resistant tuberculosis, managed and financed by MSF with 19 partner organisations across Uzbekistan, Belarus, and South Africa.

The trial enrolled 552 patients across seven clinical facilities over five years (2017–2022), with over 250 staff involved. Its headline result — that the BPaLM regimen was superior to the standard of care — directly influenced WHO guidance on DR-TB treatment. The full cost of the trial was published as €33.9 million, broken down into 27 cost items across six headings.

"The kind of answers we would get is: we have to charge high prices in order to recoup the R&D costs. However, there's no actual data and evidence to back up that claim because there's no transparency on those costs."

Roz Scourse, MSF Access Campaign

Key findings from the cost analysis included:

- 26% of total costs were at the central level (trial planning and management).
- 72% were at the trial site level, primarily driven by staff costs, external diagnostic services, and medicines.
- Bedaquiline accounted for 46% of medicine costs.
- The mean cost per enrolled patient across the whole trial was €61,460.

The response from industry was illustrative. When the analysis was presented at the WHO PPRI conference in April 2024, an industry representative argued that publishing R&D costs was simply too complex — 'like trying to find God'. Scourse noted that this argument recurs consistently in policy discussions as a barrier to transparency obligations, and that MSF's exercise demonstrated it is not credible.

BUILDING TOWARD STANDARDISATION

Following the TB-PRACTECAL analysis, MSF developed the Transparency CORE toolkit — a freely available spreadsheet tool enabling organisations to record and report clinical trial costs using the 27-item framework, with the explicit aim of building towards standardised reporting across the sector.

MSF is now conducting a parallel analysis of the endTB trial — a larger, multi-partner study — and is working with partners to develop formal standardised clinical trial cost reporting guidelines, analogous to established frameworks such as PRISMA for systematic reviews.

The goal is a 'coalition of the willing' among public-interest R&D actors — PDPs, non-profits, and public research organisations — who begin publishing their trial costs, building an evidence base and normalising what should become standard practice for any publicly funded R&D.

The connection to legislative processes was underscored by the moderators: the Horizon Europe regulation currently under negotiation will determine how public R&D funding is structured for the next several years, and joint undertaking articles on affordable access currently lack transparency provisions. Without cost data, conditions on fair pricing cannot be implemented in practice.

3. THE **MVA-BN VACCINE**: PUBLIC INVESTMENT, INEQUITABLE ACCESS

The third presentation, by Megan Whiteman of Public Citizen, provided a concrete case study in how extensive public contributions to a medical product's development can coexist with — and in some ways enable — inequitable access outcomes. The MVA-BN vaccine, marketed by Bavarian Nordic as Jynneos, illustrates a pattern that is neither unique to Mpox nor to vaccines: public funding sustains development and de-risks commercialisation, but without conditions attached, the resulting product is priced and allocated on terms that prioritise private returns over public benefit.

THE PUBLIC FOUNDATIONS OF JYNNEOS

The origins of Jynneos lie in publicly funded research. Bavarian scientists at public institutions developed the original modified vaccinia Ankara (MVA) virus between the 1950s and 1970s, and the NIH further developed its use as a viral vector. Bavarian Nordic entered into agreements with a NIH scientist and obtained exclusive access to the original viral stock from one of the German researchers — effectively privatising a publicly developed discovery.

Since entering the market, the US government alone has provided more than US\$2.3 billion to Bavarian Nordic — covering clinical trials, procurement for the national stockpile, and the development of a thermostable formulation. BARDA funded key development steps. The FDA granted the company a Priority Review Voucher in 2019 when the vaccine received regulatory approval, which Bavarian Nordic sold to an undisclosed buyer for US\$95 million. In the words of the White House itself, US government research institutions 'led the development of the JYNNEOS vaccine through preclinical evaluation, clinical trials, and advanced clinical evaluation platforms'.

TWO OUTBREAKS, PERSISTENT INEQUITY

This public investment proved decisive in ensuring an approved vaccine existed when WHO declared a global Mpox emergency in 2022 and again in 2024. But the ability to translate that investment into broad, equitable access was severely limited in both instances.

During the 2022 outbreak — in which Mpox spread to over 100 countries — Bavarian Nordic had temporarily closed its manufacturing facility, creating a critical production gap at the height of the emergency. The vast majority of available doses went to high-income countries, while lower-income countries, including those in Latin America, struggled for access.

During the 2024–25 outbreak — caused by a distinct strain and centred in Central and Western Africa — Africa CDC called for up to 10 million doses. Approximately five million were ultimately acquired through purchase or donation. A central bottleneck, identified explicitly by Africa CDC's Dr. Ngashi Ngongo, was price: Jynneos was originally priced at around US\$100 per dose or higher, with high-income countries paying less than was initially offered to Gavi and UNICEF. A negotiated lower price of US\$65 per dose was agreed, but UNICEF was ultimately unable to procure its full intended order due to a lack of funds — in part a consequence of the high per-dose cost combined with the two-dose regimen requirement.

"These secretive approaches to pricing may have resulted in unfair terms and combined with a lack of constraint on pricing, only enabled the kind of information asymmetry that could undermine timely access."

Megan Whiteman, Public Citizen

Lack of transparency compounded these barriers. At no point did Bavarian Nordic publicly justify its pricing in relation to its R&D costs or the public investment it had received. The information asymmetry between the company and procuring organisations — Gavi, UNICEF, and African governments — limited the scope for effective negotiation. Public Citizen's research found that the US government had itself paid a lower price for the vaccine than what was offered to Gavi and UNICEF as the 'lowest market price'. Additional access barriers included slow regulatory approval processes in African countries and insufficient evidence for use in specific vulnerable populations such as children.

CONDITIONS AS THE CORRECTIVE MECHANISM

Whiteman outlined the policy toolkit most likely to have altered these outcomes — and that should structure future agreements where public money funds medical product development:

- Transparency conditions — proactive publication of funding agreements, at minimum including terms related to access and pricing.
- Reasonable pricing conditions — including provisions defining how price should be set in relation to costs, reasonable profit, and public investment.
- Global access conditions — humanitarian pricing tiers, regulatory approval obligations in low-income countries, provisions enabling donations, and requirements for technology transfer or licensing to expand the supplier base, particularly in Africa.

Recent policy developments suggest a growing — if still incomplete — consensus. The NIH has adopted a new access planning policy. BARDA now includes reasonable pricing as a regular component of contract negotiations. The Pandemic Agreement, adopted in 2025, includes provisions on access conditionalities in R&D and procurement agreements and on transparency in those agreements. These are meaningful steps, though the enforcement mechanisms of some — including the NIH policy — were noted to rely largely on voluntary follow-up by companies rather than binding requirements.

4. THE INFORMATION ASYMMETRY AT THE HEART OF PRICING

A cross-cutting theme of the webinar was information asymmetry — the structural imbalance between what pharmaceutical companies know about their own costs, public support, and pricing strategies, and what public authorities, procurement bodies, and civil society can access. This asymmetry is not incidental; it is a governance feature that systematically favours private actors in negotiations that determine public health outcomes.

Three dimensions of this asymmetry emerged from the discussion:

- Public contributions are poorly mapped. Despite their scale, contributions from national innovation funds, regional subsidies, academic spin-off support, and indirect infrastructure provision are systematically under-documented. Even EU and NIH funding — which is relatively well reported — is not compiled in a form that public health authorities can easily use in pricing or procurement negotiations.

- R&D costs are deliberately opaque. The 100-fold range in published cost estimates is not a reflection of genuine complexity — it is a consequence of a system in which companies are not required to disclose actual cost data. Industry arguments that publishing costs is 'too complex' serve to maintain this opacity and the pricing power it confers.
- Access conditionalities lack a cost baseline. Whether in the context of the Pandemic Agreement, Horizon Europe's joint undertakings, or national reimbursement negotiations, conditions designed to ensure public benefit cannot be calibrated or enforced without reliable cost data. Transparency and conditionality are not separate issues — transparency is a precondition for conditionality to work.

The question raised during the discussion — where is the greatest leverage today to convert transparency into real negotiating power? — drew different responses reflecting different scales of action. Claudia Wild emphasised the potential of joint procurement platforms (such as BeNeLuxA or Finosa) to build collective bargaining power: single countries, especially small ones like Austria, lack the market weight to use this information effectively. Megan Whiteman emphasised conditions in funding agreements as the most enforceable mechanism, ideally embedded early in the development process rather than negotiated retrospectively during emergencies. Roz Scourse emphasised the need to reignite implementation of the 2019 WHO Transparency Resolution, which remains largely unimplemented.

A specific concern raised by the moderators was the Horizon Europe negotiation currently underway: the next framework programme will determine how EU public R&D funding is structured for the coming decade, and there is a narrow but real window to embed transparency and access conditions into the regulation's core architecture. Cyprus and Ireland hold presidency responsibilities at the relevant moment.

5. CROSS-CUTTING POLICY QUESTIONS

The webinar identified a set of critical questions that should guide the assessment of pharmaceutical funding and access policies:

- Are the actual costs of R&D — including public contributions — being disclosed in a form that enables fair price determination and evidence-based conditionalities?
- Do procurement and reimbursement negotiations have access to comprehensive, standardised information about public contributions, or are they systematically disadvantaged by information asymmetry?

- Are access conditionalities in public funding agreements — covering pricing, transparency, technology transfer, and global supply — embedded at the design stage, or left to be negotiated under emergency conditions?
- Are enforcement mechanisms for transparency and access obligations binding, or primarily voluntary?
- Is the WHO Transparency Resolution — still largely unimplemented seven years after adoption — receiving the political attention required to restore momentum?
- Does the next Horizon Europe regulation embed transparency and access conditions that give Article 57 of the EU Pharmaceutical Directive practical effect?

6. IMPLICATIONS FOR POLICY AND ADVOCACY

The webinar concluded with a strong sense that the current moment offers real — if narrow — opportunities for progress on transparency and access conditionalities, and that civil society engagement is essential to keeping those opportunities open.

Three immediate policy processes were identified as priorities:

EXAMPLE 1: THE EU PHARMACEUTICAL DIRECTIVE AND ARTICLE 57

Article 57 of the negotiated EU Pharmaceutical Directive requires companies to declare public financial support received during drug development. This is a significant legal precedent, but without robust implementation guidance, enforcement mechanisms, and a control role for EMA, it risks becoming symbolic. Civil society and public health advocates should push for implementing regulations that give Article 57 teeth: binding reporting formats, sanctions for non-disclosure, and the establishment of a publicly accessible database of declared contributions.

EXAMPLE 2: HORIZON EUROPE AND ACCESS CONDITIONS IN JOINT UNDERTAKINGS

The next Horizon Europe framework is under negotiation, and joint undertaking regulations already include provisions on affordable access. However, as the moderators noted, these provisions do not currently specify transparency on R&D costs as a condition — creating a gap between the access ambition and the information basis needed to operationalise it. Amendments linking public funding to cost disclosure requirements would significantly strengthen the framework's accountability architecture.

EXAMPLE 3: THE PANDEMIC AGREEMENT AND ITS IMPLEMENTATION

The Pandemic Agreement — adopted in 2025 — includes provisions on access conditionalities in R&D and procurement agreements and on transparency. The

challenge now is implementation. As the Mpox case illustrates, well-designed global norms on conditionality are undermined when individual funding agreements are negotiated without transparency, under information asymmetry, and without enforcement. Civil society monitoring of how the Agreement's transparency and access provisions are transposed into actual contracts will be critical.

Across all three processes, the core advocacy message from the webinar is the same: transparency is not an end in itself — it is the enabling condition for every other access lever. Fair pricing cannot be negotiated without cost data. Conditions on public funding cannot be enforced without knowing what public contributions were made. Democratic accountability for medicines policy requires that the public can see who paid, who benefited, and on what terms.