

# The rising cost of **Long COVID and ME/CFS** in Germany: 2026 update

April 2026



## Version

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## Data availability

This modelling study is based on secondary data obtained from multiple publicly-accessible sources. The specific data sources used are referenced within the text (including in the Annexes) and included in the reference list wherever possible in the original report from 2025:

Daniell J et al. (2025) [The rising cost of Long COVID and ME/CFS in Germany](#). Hamburg and Karlsruhe: ME/CFS Research Foundation and Risklayer.

All data are publicly available for verification and further research, via Johannes Brand. A copy of the model can be found on GitHub at <https://github.com/risklayer>.

## Conflict of interest

All authors declare that they have no competing financial and non-financial conflicts of interest.

## Suggested citation

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# Executive summary

**This report is an update of The rising cost of Long COVID and ME/CFS in Germany, in which we modelled the prevalence and cost of Long COVID and ME/CFS in Germany for the five-year period from 2020 to 2024. Here, we use new data to extend the model to the six-year period from 2020 to 2025, and draw out targeted policy recommendations relevant to the new policy context, as funding commitments were made by the German government following the initial report.**

In our 2025 report, we modelled the growing prevalence and societal cost of Long COVID and ME/CFS in Germany, and highlighted the disproportionately low levels of investment in research and innovation around these conditions. Several months later, the Federal Government of Germany announced an investment of €500 million in research funding under the *National Decade Against Post-infectious Diseases* (herein the *National Decade*) from 2026 to 2036. This major policy initiative aims to identify underlying disease mechanisms and develop viable treatment options for post-infectious diseases, including Long COVID and ME/CFS.

This 2026 update shows that Long COVID and ME/CFS continue to affect a substantial share of the population in Germany. At the end of 2025, there were around 757,000 active cases of Long COVID and 657,000 active cases of ME/CFS. In total, more than 1.4 million people were living with these chronic and debilitating conditions at the end of 2025, often leading to lasting functional impairment and long-term work incapacity. This high figure is not unexpected, given SARS-CoV-2 continues to circulate and cause post-infectious diseases, no viable treatment options are available, and policy commitments like the *National Decade* take time to drive systemic, measurable change.

**Our updated analysis reported here estimates that the costs of Long COVID (€31.6 billion) and ME/CFS (€32.8 billion) each contributed roughly half of a combined €64.4 billion annual cost in Germany in 2025, equivalent to approximately 1.44% of national GDP. For the six-year period from 2020 to 2025, the model calculates a total cumulative cost of Long COVID and ME/CFS of €318.8 billion.**

Where possible, we have also included in this report an updated literature review. Epidemiological and economic research on Long COVID and ME/CFS remains relatively limited. Where it does exist, it aligns with our findings, and continues to indicate a substantial current and future burden of post-infectious diseases on health systems and society. Several recent studies provide new estimates of, for example, the prevalence, cost, and risk of Long COVID. Following careful consideration, we have not incorporated these estimates into the current update for reasons we explain in the report. As part of future updates, we will evaluate new findings as they emerge and may revise the data model.

In the context of the *National Decade*, our updated findings help identify effective targets for investment of this significant national policy programme and other related initiatives. Our findings point to five key recommendations. First, invest into biomarkers, diagnostics, and treatments, in order to improve the low rate of recovery, one of the key cost drivers. Second, close the biomedical funding gap in order to change the disease state. Third, accelerate research through learning and feedback loops, as efficiency gains will start to bring costs down sooner. Fourth, incentivise collaboration and open science for greater pace, innovation, and real-world impact. Fifth, improve data collection to evaluate policy effectiveness and reduce the need for modelling. Until the latter is ensured, our data model on the prevalence and cost of Long COVID and ME/CFS remains the most up-to-date data basis available and will continue to play an important role in informing policy and decision-making.

# Zusammenfassung

**Dieser Bericht ist eine Aktualisierung der Studie „The rising cost of Long COVID and ME/CFS in Germany“, in der wir die Prävalenz und die Kosten von Long COVID und ME/CFS in Deutschland für den Fünfjahreszeitraum von 2020 bis 2024 modelliert haben. Der Bericht enthält neu verfügbare Daten für den Sechsjahreszeitraum von 2020 bis 2025 und liefert politische Handlungsempfehlungen auf Grundlage der nach Erscheinen des ersten Berichts angekündigten Forschungsfinanzierung der Deutschen Bundesregierung.**

In unserem ersten Bericht haben wir die steigende Prävalenz und die wachsenden gesellschaftlichen Kosten von Long COVID und ME/CFS in Deutschland dokumentiert und die unverhältnismäßig geringen Investitionen in Forschung und Innovation im Bereich dieser Erkrankungen hervorgehoben. Einige Monate später kündigte die Bundesregierung im Rahmen der „Nationalen Dekade gegen Postinfektiöse Erkrankungen“ (*Nationale Dekade*) für den Zeitraum 2026 bis 2036 Forschungsinvestitionen in Höhe von 500 Millionen Euro an. Diese politische Initiative zielt darauf ab, die ursächlichen Krankheitsmechanismen zu identifizieren und wirksame Behandlungsoptionen für postinfektiöse Erkrankungen, einschließlich Long COVID und ME/CFS, zu entwickeln.

Unsere aktualisierte Analyse zeigt, dass Long COVID und ME/CFS weiterhin einen erheblichen Teil der Bevölkerung in Deutschland betreffen. Ende 2025 gab es rund 757.000 aktive Long COVID-Fälle und 657.000 aktive ME/CFS-Fälle. Insgesamt lebten Ende 2025 mehr als 1,4 Millionen Menschen mit diesen chronischen und oft schweren Erkrankungen, die häufig zu dauerhaften Funktionseinschränkungen und langfristiger Erwerbsunfähigkeit führen. Diese hohe Zahl ist nicht unerwartet angesichts der anhaltenden Verbreitung von SARS-CoV-2, fehlender Therapieoptionen und der Tatsache, dass Initiativen wie die *Nationale Dekade* Zeit benötigen, um systemische und messbare Veränderungen zu bewirken.

**Unsere vorliegende Analyse zeigt, dass die Kosten von Long COVID (31,6 Milliarden Euro) und ME/CFS (32,8 Milliarden Euro) jeweils etwa die Hälfte der kombinierten jährlichen Kosten von 64,4 Milliarden Euro in Deutschland im Jahr 2025 ausmachten, was etwa 1,44 % des nationalen BIP entspricht.**

**Für den Sechsjahreszeitraum von 2020 bis 2025 berechnet das Datenmodell kumulierte Gesamtkosten von Long COVID und ME/CFS in Höhe von 318,8 Milliarden Euro.**

Wo verfügbar, haben wir in diesem Bericht eine aktualisierte Literaturübersicht eingefügt. Die epidemiologische und ökonomische Forschung zu Long COVID und ME/CFS ist nach wie vor begrenzt. Vorhandene Studien decken sich mit unseren Ergebnissen und weisen auf eine erhebliche gegenwärtige und zukünftige Belastung von Gesundheitssystem und Gesellschaft durch postinfektiöse Erkrankungen hin. Einige wenige Studien liefern neue Schätzungen, beispielsweise zur Prävalenz, den Kosten und dem Risiko von Long COVID. Diese Schätzungen sind nach sorgfältiger Prüfung aus im Bericht erläuterten Gründen nicht in die vorliegende Aktualisierung eingeflossen. Im Rahmen zukünftiger Aktualisierungen werden wir neue Erkenntnisse bewerten und bei Bedarf das Datenmodell überarbeiten.

Im Kontext der *Nationalen Dekade* tragen unsere neuen Ergebnisse dazu bei, effektive Investitionsziele für dieses bedeutende nationale Forschungsprogramm zu identifizieren. Unsere Ergebnisse führen zu fünf zentralen Empfehlungen: Erstens, in Biomarker, Diagnostik und Therapien investieren, um die niedrige Genesungsrate zu erhöhen, einen der Hauptkostentreiber. Zweitens, die Finanzierungslücke im biomedizinischen Bereich schließen, um den Krankheitszustand zu verändern. Drittens, Forschung durch Lern- und Feedbackschleifen beschleunigen, da Effizienzsteigerungen die Kosten schneller senken werden. Viertens, Anreize für Zusammenarbeit und Open Science schaffen, um mehr Geschwindigkeit, Innovation und Auswirkungen auf tatsächliche Lebensrealitäten zu erzielen. Fünftens, die Datenerhebung zur Bewertung der politischen Wirksamkeit verbessern und somit den Modellierungsbedarf zu reduzieren. Bis letzteres gewährleistet ist, bleibt unser Datenmodell zur Prävalenz und den Kosten von Long COVID und ME/CFS die aktuellste verfügbare Datengrundlage und wird weiterhin eine wichtige Rolle für politische Maßnahmen und Entscheidungsfindung spielen.

## About this report

In our May 2025 report, [The rising cost of Long COVID and ME/CFS in Germany](#), (Daniell et al., 2025) we modelled the prevalence and cost of Long COVID and ME/CFS in Germany for the five-year period from 2020 to 2024. The figures we reported played a key role in informing decision-making around the Government of Germany's major policy initiative, the *National Decade Against Post-infectious Diseases* (herein the *National Decade*), which will see €500 million invested, between 2026 and 2036, into

improving outcomes around post-infectious health conditions. One year on from that initial report, we have re-run the model with updated data — covering the prevalence and cost of Long COVID and ME/CFS for the year 2025 — to ensure decision-making continues to be informed by the latest evidence. This brief update report summarises our approach and our findings, and serves as an addendum to the original report which contains a comprehensive discussion of literature, approach and limitations.

## Key definitions

To ensure consistency in our analysis, this update continues to model the societal cost of Long COVID and ME/CFS together due to their shared characteristics, and retains the definitions established in our first report:

- **Long COVID:** Following the framework of the German Federal Ministry of Health, Long COVID serves as an umbrella term for all multi-systemic,

COVID-19-related symptoms that persist beyond four weeks following acute SARS-CoV-2 infection.

- **ME/CFS:** Defined according to Hoffmann et al. (2024), ME/CFS is a debilitating chronic condition characterised by post-exertional malaise (PEM), severe fatigue, and cognitive dysfunction, requiring symptom persistence for at least six months for a diagnosis.

## Policy developments since our last report

In November 2025, the Federal Government of Germany announced the launch of the *National Decade Against Post-infectious Diseases*. Led by the Federal Ministry of Research, Technology, and Space (BMFTR), this initiative responds to the urgent need for research and innovation on ME/CFS and Long COVID and severe shortage of targeted medical care, issues consistently raised by patient organisations over many years, and reinforced by our initial analysis (Daniell et al., 2025). Partners represented on the *National Decade's* steering committee include university and non-university research institutions, ministries at state and federal levels, patient representatives, the Innovation Fund of the Federal Joint Committee (G-BA) (the medical self-governing body representing insurers, hospitals and physicians), the Association of Research-based Pharmaceutical Companies (vfa), all with varying existing levels of expertise in Long COVID and ME/CFS.

The *National Decade* aims to decipher the causes and mechanisms of post-infectious diseases, with the goal of developing viable treatment options, and sits in a broader ecosystem of activity. It commits a total of €500 million in funding, €50 million/year for the decade 2026—2036, on “pathophysiology and immunology, diagnostics and biomarkers, neurology, mental health, and long-term consequences of ME/CFS” (BMFTR, 2026). This will position Germany as one of the world's leading research hubs for these health conditions. Measures include support for clinical trials, large genome sequencing initiatives, collection and analyses of comprehensive medical data, and promoting early-career researchers and expanding interdisciplinary research networks. At this point in time, the government has not yet announced the details of funding allocation or priority areas, including the share of funding designated for biomedical research. Our aim with this report is to inform next steps in the design and implementation of this agenda.

# Approach and Adjustments

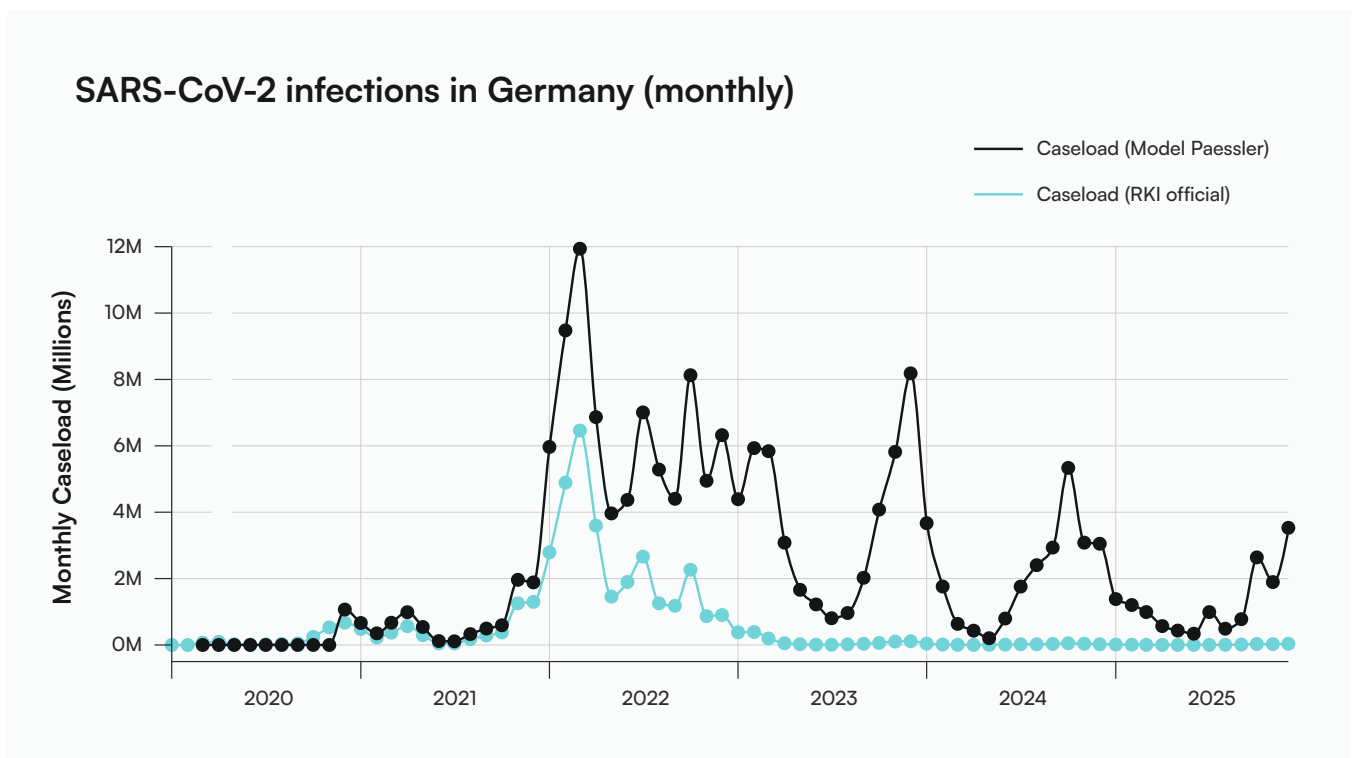
This updated report centres on new caseload data, the associated cost, and a short review of recent literature. We started with the model detailed in our original report, and used updated data to re-run it. As we learn more about Long COVID and ME/CFS, especially

through new research, action, and surveillance, we expect that a full overhaul of the model and assumptions made therein will eventually be required. At this time, however, there is insufficient new evidence.

## Updating caseload data

As a proportion of people infected by SARS-CoV-2 go on to develop Long COVID and/or ME/CFS, understanding the infection caseload is key to our model. However, the true incidence of SARS-CoV-2 infections is not captured in official records as we lack the surveillance mechanisms to capture them; with no

requirement to test or report for these infections, we know that official data underestimate total caseload. As a result, modelling continues to be the best available tool for quantifying the infection caseload in Germany. It indicates that more than ten million SARS-CoV-2 infections still occur annually in Germany (Figure 1).



**Figure 1:** SARS-CoV-2 infection caseload in Germany, official data from Robert Koch Institute (RKI) compared to corrected model data from Paessler et al. (2026). Official data do not capture all cases; modelling suggests that in 2025, the actual number of infections was between 13 and 15 million, which was 80-200 times higher than the officially recorded figures.

# A note on our modelling approach

As described in our original report, our modelling uses a dynamic Monte Carlo simulation to trace individual disease progression through the entire German population (roughly 84 million people). This stochastic model applies probability distributions (rather than fixed values) to factor in real-world variables like reinfections, demographics, and the "long-tail" duration of symptoms. By calculating a daily severity index for each person, the model translates

these complex, intersecting health trajectories into societal costs, providing policymakers with a crucial tool to anticipate the ongoing strain on healthcare, labour markets, and welfare systems.

A comprehensive description of our modelling approach, underlying assumptions, and limitations is contained in our initial report (Daniell et al., 2025).

## Running the 2026 model update

We initially attempted to run a single, continuous simulation from 2020 through 2025. However, due to the inherent randomness of Monte Carlo simulations where complex, interacting probabilities produce slight variances in each run, it was not possible to perfectly replicate the exact 2020—2024 numbers published in our first report.

Given the importance of maintaining consistent historical data for policy evaluation, we instead executed 2025 as a standalone model run.

This 2025 simulation uses the final endpoints and outputs of the 2020—2024 model as its starting baseline. The fundamental disease trends remain the same, and this phased approach guarantees consistency with our past reporting while robustly extending the forecast into 2025.

To ensure comparability to the original report, monetary values in this updated report reflect values in Euros as of 2024 without taking into account inflation adjustment to 2025 Euros.

## New literature since the initial release

Our review of literature published since the release of the initial report identified only a limited number of new studies. Overall, new and existing research is broadly in line with our findings. Several studies point to the considerable societal cost of post-infectious diseases, which may already surpass that of other chronic diseases (Bansal, 2025; Bartsch et al., 2025). Hou et al. (2025) concluded that the prevalence of Long COVID persists over time, while Peine et al. (2025) provided additional evidence that vaccination lowers the risk of developing Long COVID. One study examining the US research funding landscape found that Long COVID received much less funding than its disability burden warrants, while ME/CFS was identified as the most underfunded condition relative to its years lived with disability (Bonuck et al., 2026).

We decided not to adjust the model based on new studies at this time for several reasons: an absence of validated, standardised case definitions for Long COVID and its phenotype subgroups, the lack of standardised infection reporting combined with a high risk of underreporting in contexts where self-testing rates declined from 2023 onwards

(de Bruijn et al., 2025); reported low certainty of evidence (Peine et al., 2025); and, the relatively small changes these particular studies would make to our final figures. As more research emerges, it could help to overhaul our model in future updates.

We did not draw upon a recent study by the Organisation for Economic Co-operation and Development (OECD) on the costs of Long COVID as its release coincided with our update report going to press (OECD, 2026). While the OECD study uses different parameters, methods, data, and assumptions compared to ours, and does not discuss ME/CFS, it also finds that the cost of Long COVID poses a significant burden to society.

Results from ongoing or projected publicly-funded research addressing the prevalence and cost of Long COVID and ME/CFS in Germany, which we mentioned in our first report, are expected earliest at the end of 2026, and more likely in 2027 and beyond. Accordingly, this update report presents the most recent and comprehensive data available to date.

# Results

According to our updated modelling, at the end of 2025, there were around 757,000 active Long COVID cases and 657,000 active ME/CFS cases in Germany, with a combined prevalence of over 1.4 million cases. The resulting costs are estimated at €31.6 billion for Long COVID and €32.8 billion for

ME/CFS. The combined cost of €64.4 billion equates to approximately 1.44% of national gross domestic product (GDP). For the six-year period 2020–2025, the total cumulative cost of Long COVID and ME/CFS in Germany was estimated to be €318.8 billion.

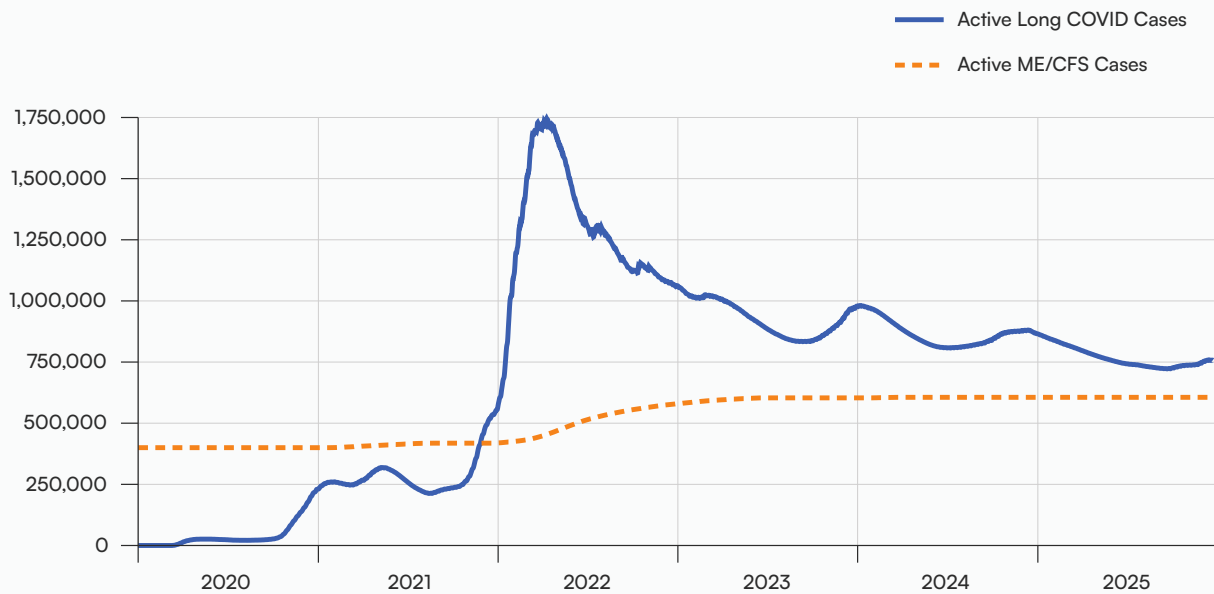
## Estimated caseloads and trends

The number of ME/CFS cases continued to rise steadily to around 657,000 cases at the end of 2025 (Figure 2). Driven by a steady progression of cases from the Long COVID to ME/CFS pool, and heavily constrained by low recovery rates, the ME/CFS caseload will likely continue its upward trajectory in the coming years.

Meanwhile, the number of active Long COVID cases in Germany decreased in 2025.

In 2022, Long COVID cases peaked at 1.75 million and then receded to around 757,000 at the end of 2025. There are still fluctuations in the simulated Long COVID case numbers, which are determined by the frequency of distinct infection waves, new variants of SARS-CoV-2, the protective effect of cumulative vaccinations, the incidence of reinfection, and varying recovery rates.

### Active Long COVID and ME/CFS cases in Germany over time



**Figure 2:** Active Long COVID cases per day and active ME/CFS cases per day in Germany (average of four models), 2020–2025. The number of ME/CFS cases increased during the pandemic, while Long COVID cases peaked in 2022, before reducing to a more stable level as SARS-CoV-2 shifted from pandemic to endemic in the population.

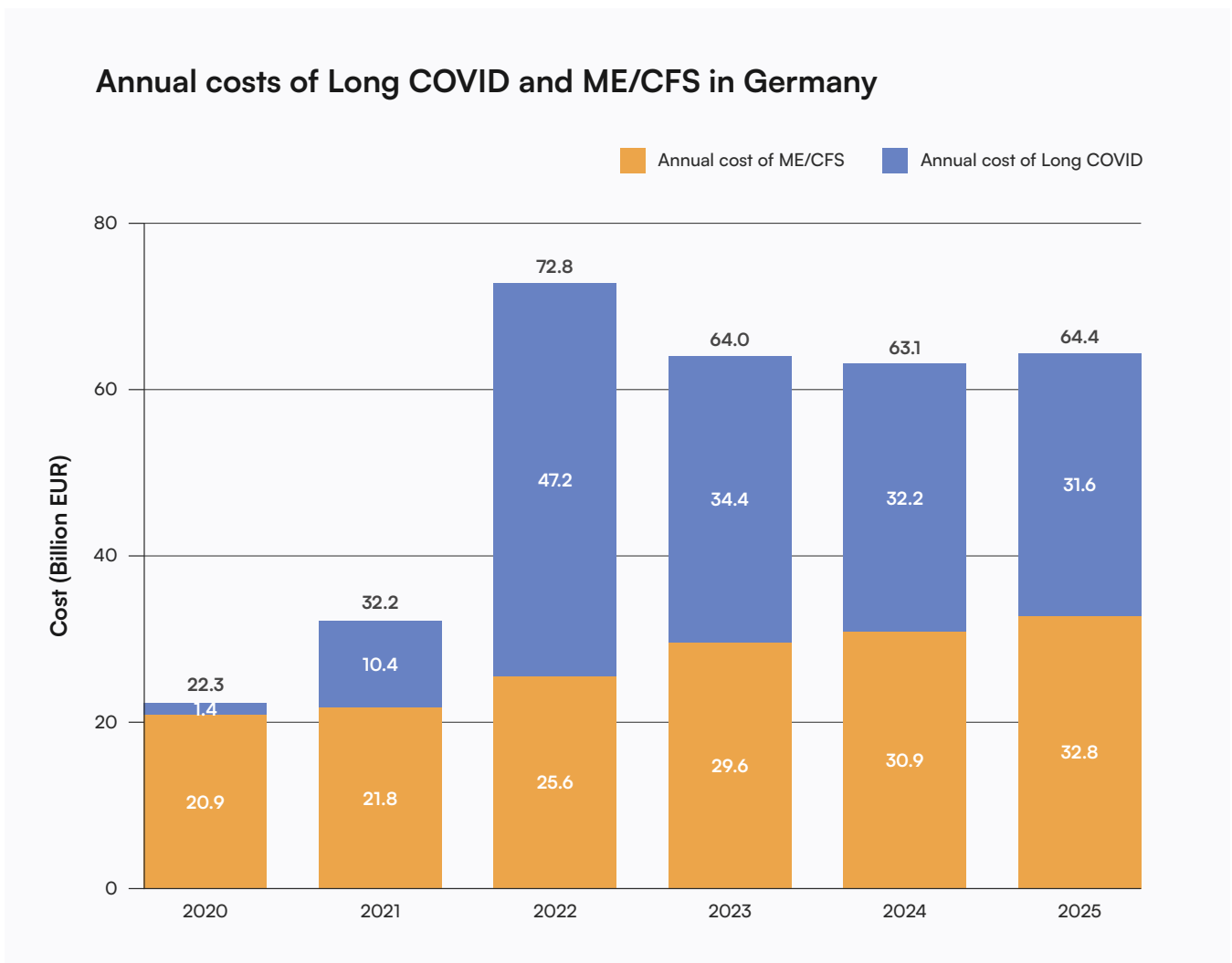
# Estimated costs of Long COVID and ME/CFS

Together, Long COVID and ME/CFS have cost the German economy €318.8 billion since the COVID-19 pandemic was declared in January 2020. For the year 2025, our modelling estimates that the combined societal cost (personal, employer, medical and society losses) of these conditions was €64.4 billion (Figure 3 and Table 1). While the annual costs of Long COVID peaked during the 2022 infection wave at €47.2 billion and have since stabilised at €31.6 billion at the end of 2025, the costs associated with ME/CFS continue to climb. Driven by a steady rise in new cases outpacing recoveries, ME/CFS costs reached €32.8 billion in 2025, surpassing the annual societal cost of Long COVID.

One thing to note in Table 1 is a relatively small increase in ME/CFS case numbers from 2024 to 2025 against a disproportionately large increase in costs during that same time. This can be explained by cumulative

effects over time. New cases do drive increasing costs; in addition, costs of existing cases accumulate, and the longer we follow people in the model, some cases become more severe and few people recover. A shift from mild to severe ME/CFS over time drives the average cost per case (see Annex 2 in our initial report for a breakdown of the severity multipliers). While there is some seasonal fluctuation in SARS-CoV-2 infections in Germany (Figures 1 and 4), it is striking that the overall cost persists at a level of €5–6 billion per month since 2022, with no sign of decreasing (Figure 4).

Overall, Long COVID and ME/CFS have consistently consumed more than 1.4% of Germany's GDP since 2022 (Figure 5). The annual cost of ME/CFS and Long COVID as a percentage of national GDP highlights the substantial and lasting impact of these related conditions on Germany's economy and society.

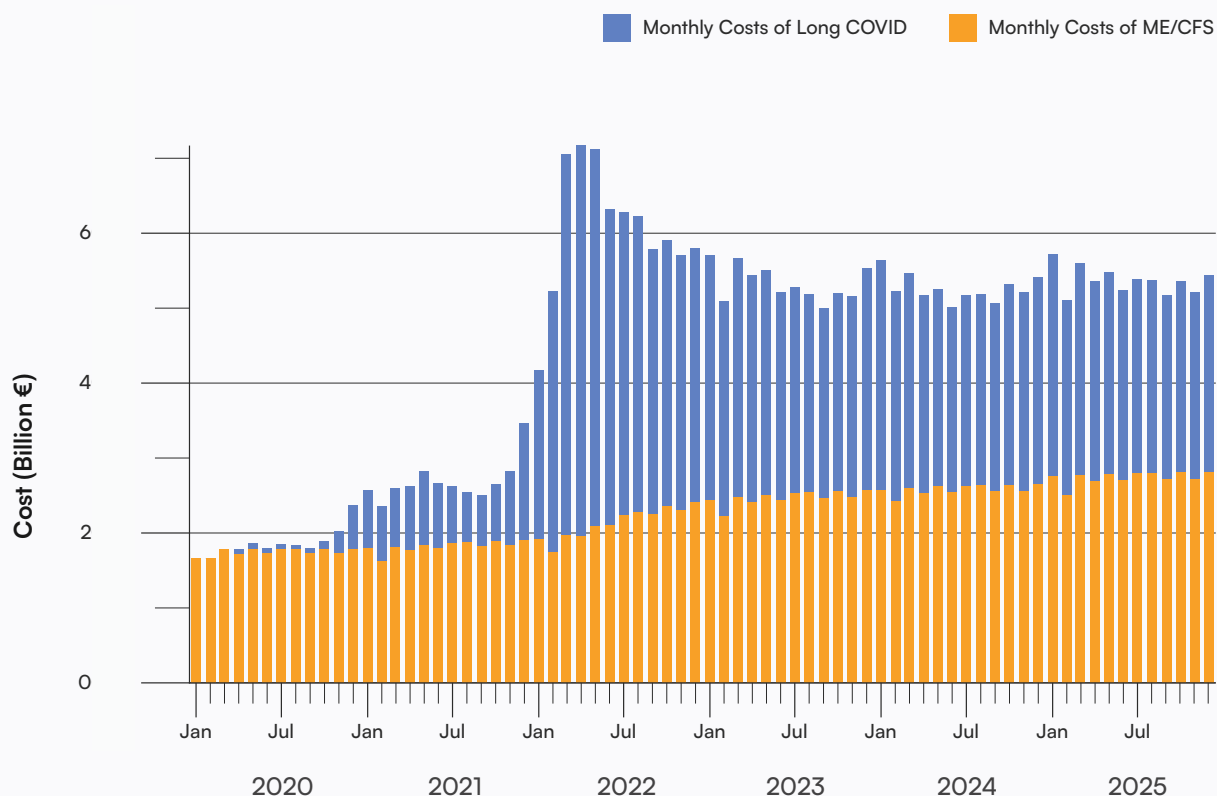


**Figure 3:** Annual costs of Long COVID and ME/CFS in Germany (average of four models), 2020–2025 (in billions of Euros). Corresponding numbers of Long COVID and ME/CFS cases at year end are shown in Table 1.

**Table 1: Cases and costs of Long COVID and ME/CFS in Germany, 2020—2025.** Average of the four variations of the model developed.

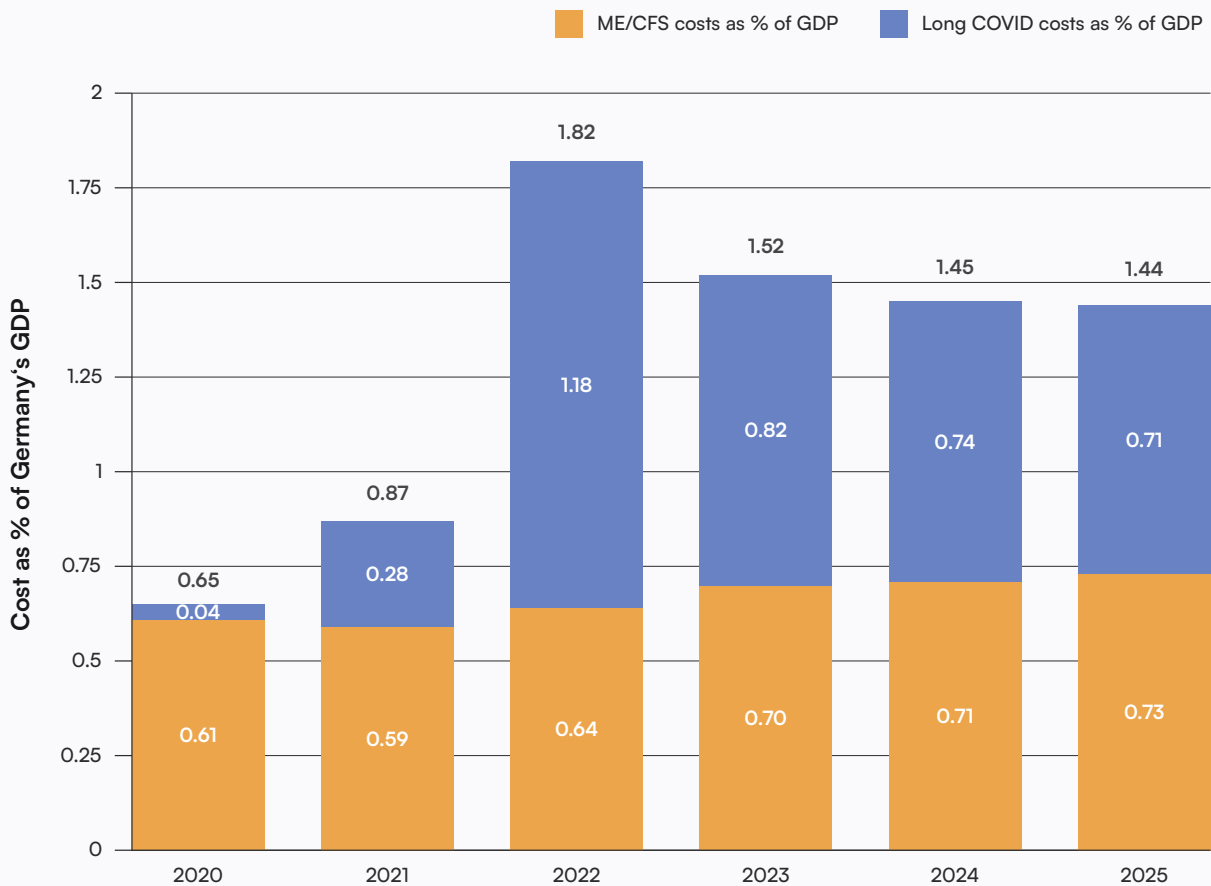
| Year         | Long COVID |                   |                  | ME/CFS    |                   |                  | Long COVID & ME/CFS       |
|--------------|------------|-------------------|------------------|-----------|-------------------|------------------|---------------------------|
|              | New cases  | Cases at year end | Cost (€ billion) | New cases | Cases at year end | Cost (€ billion) | Combined cost (€ billion) |
| 2020         | 272,829    | 227,560           | 1.4              | 3,481     | 403,432           | 20.9             | 22.3                      |
| 2021         | 805,773    | 547,306           | 10.4             | 36,593    | 438,896           | 21.8             | 32.2                      |
| 2022         | 2,743,384  | 1,064,373         | 47.2             | 165,849   | 598,620           | 25.6             | 72.8                      |
| 2023         | 527,594    | 970,917           | 34.4             | 46,168    | 635,838           | 29.6             | 64.0                      |
| 2024         | 282,381    | 871,086           | 32.2             | 28,792    | 650,183           | 30.9             | 63.1                      |
| 2025         | 164,976    | 756,808           | 31.6             | 20,870    | 656,951           | 32.8             | 64.4                      |
| <b>Total</b> |            |                   | <b>157.2</b>     |           |                   | <b>161.6</b>     | <b>318.8</b>              |

### Monthly costs of Long COVID and ME/CFS in Germany



**Figure 4:** Monthly costs of Long COVID and ME/CFS in Germany (average of four models), 2020—2025 (in billions of Euros). The model output here gives the monthly costs of Long COVID (blue) and ME/CFS (orange) for each month since the beginning of 2020.

## Annual costs of Long COVID and ME/CFS as % of Germany's GDP



**Figure 5:** Model-based costs of Long COVID and ME/CFS per year for 2020–2025. Costs are mapped against the annual GDP of Germany (Eurostat, 2026).

## Model plausibility check and comparison

As with our initial report, we benchmarked our 2026 update against other available international economic evaluations. Our conclusion that these overlapping conditions continue to account for roughly 1.4% of Germany's GDP strongly aligns with other broader economic estimates of Long COVID and ME/CFS that

are discussed in detail in our initial report (Daniell et al., 2025, Annex 1). To the best of our knowledge, no research has been published that would fundamentally change any of the model's parameters or assumptions.

# Discussion and recommendations

The sustained societal cost of Long COVID and ME/CFS reported in this update, totaling €318.8 billion in 2020–2025 and consuming more than 1.4% of Germany’s annual GDP in 2022–2025, confirms these diseases have a significant impact on the welfare of Germany’s society, with this trend likely to continue. Individuals who develop these diseases — over 1.4 million in 2025 alone — bear a significant burden. The recent launch of the *National Decade Against Post-*

*infectious Diseases* represents a crucial, positive shift in addressing this challenge. At the time of publication of this update, the implementation strategy, timeline, and priorities of the *National Decade* are not yet in the public domain. Improving outcomes and reducing costs for individuals and society will depend on smart, rapid, and strategic allocation of the research funding under this policy agenda. Our updated modelling is in part intended to help inform this next step.

## Invest into biomarkers, diagnostics, and treatments

According to our model, one of the main factors driving the societal cost of Long COVID and ME/CFS in Germany is the low rate of recovery from these diseases, ME/CFS in particular. This points to a major opportunity space around clinically-relevant research.

Targeted investments under the *National Decade* prioritising the rapid development of safe, effective, and widely-available treatments would drive down costs and significantly improve the lives of people living with post-infectious diseases. Early investments in treatment development would also lay the foundation for longer-term basic research to understand disease

mechanisms. It requires government to both invest in research on biomarkers, diagnostics and therapies, and establish clear incentives and requirements around safety, access and open science.

There is also work to be done to improve patient outcomes, advance science and drive down the costs calculated in this model which is beyond the scope of the *National Decade*. Simultaneously laying the foundations for a rapid path to translation and implementation with and through other government departments and organisations is of key importance.

## Close the biomedical funding gap

At the end of 2025, research on biomarkers, diagnostics, and therapies had accounted for only 22% (€50 million) of the cumulative total €221 million in funding allocated to ME/CFS and Long COVID research by the Federal Government of Germany since 2022<sup>1</sup>. No more than 18% (€35–40 million) of this funding to date has been allocated to biomedical ME/CFS research, where ‘biomedical’ broadly refers to research at the intersections of biology and medicine, including physiology, genetics, pharmacology, molecular biology, biomedical engineering, bioinformatics, immunology, microbiology and more (ME/CFS Research Foundation, 2025).

In contrast, approximately €157 million (or 71%) of all federal research funding for these diseases to date has been directed toward healthcare services

research, including measures such as rehabilitation and psychotherapy (ME/CFS Research Foundation, 2025). While the latter interventions assist some patients in managing their illness, they do not change the disease state, especially in people living with ME/CFS and Long COVID characterised by post-exertional malaise (PEM) (Grande et al., 2023; Hammer et al., 2024; Thoma et al., 2024), and are thereby unlikely to reduce the societal costs reported here.

Our model points to key leverage points for reducing the cost of Long COVID and ME/CFS around finding effective treatments and improving diagnostics (and so improving data and tailored care), alongside reducing infection rates (which we discuss in more detail in our initial report).

<sup>1</sup> The total sum of €221 million in research funding allocated to date includes funds to be spent in 2026 and beyond. It does not include funding under the newly announced *National Decade*.

Closing the significant biomedical funding gap around these conditions in and through the *National Decade* agenda is therefore key to reducing costs and improving outcomes.

This could include: (a) prioritising research on identifying pathophysiological disease mechanisms

and establishing reliable diagnostics, with the aim of defining disease phenotypes and stratifying patient subgroups; (b) fast-tracking the development of viable pharmacological treatment options by trialing the repurposing of existing drugs and development of novel compounds; and, (c) inviting emerging fields of biomedicine to innovate in this area.

## Accelerate research through learning and feedback loops

Our updated model reinforces how time-critical change is in this area, with costs continuing to mount even as new policy and funding is developed and deployed. One way the *National Decade* can expedite change is to support research infrastructures and networks of expertise in Germany — where expertise includes patient experts and managers alongside scientists and healthcare practitioners — to accelerate in parallel the generation, validation, implementation and scaling of already existing and still-to-be-generated evidence from Long COVID and ME/CFS research.

One guiding principle must be to maximise the efficiency and speed with which effective therapies can be made available to patients, alongside safety and accessibility. This could be achieved, for example, by (a) rolling out basic, translational, and clinical research (including in the form of drug trials) at an early stage at the same time, (b) using existing infrastructure such

as adaptive platform trials (see e.g. The Adaptive Platform Trials Coalition, 2019), (c) enhancing feedback loops through collective work, and (d) enabling the participation of regulators and the private sector.

When it comes to creating, awarding and administering research funding, lessons from past shortcomings should be acknowledged and addressed in future. Research commissioning should include clear guidelines on definitions, diagnostic and inclusion criteria, with incentives for sharing lessons learned. Studies with overly broad inclusion criteria or insufficient emphasis on subgroup analyses which have often resulted in diluted findings should be avoided (Goxhaj et al., 2025). There are also opportunities for efficiency in harmonising studies and trials to ensure the timely and efficient use of resources and comparability of results.

## Incentivise collaboration and open science

The successful development of our model is underpinned by bringing together diverse types of expertise to deliver a research outcome that is open to public sharing and scrutiny. Such collaboration and openness can lead to greater pace, innovation and real-world impact of research, without compromising quality. For this reason, another guiding principle that would benefit the *National Decade* is to incentivise open data and collaboration rather than competitiveness at all stages of delivery.

The *National Decade* should continue to build on the accumulated evidence and knowledge from

ME/CFS and Long COVID research in Germany and internationally — both published and in the form of experience. Bringing together medical practitioners with direct experience in diagnosing and/or treating these diseases, patient experts and people with lived experience, in all stages of the work — from strategic decision making to designing calls for funding, reviewing funding proposals to implementing research — will ensure Germany capitalises on the landscape of expertise it has already fostered, and which sits behind the *National Decade*.

# Improve data collection

In this 2026 update, our model continues to point to the importance of reducing the overall SARS-CoV-2 infection load throughout the population. Our past recommendations relating to public health measures to prevent the spread of infections, including improving air quality, are still relevant here.

In addition, there is a need to maintain existing and build improved data collection infrastructure for infectious diseases (e.g. by continuing RKI's wastewater surveillance AMELAG). Improved disease surveillance will be necessary to better identify hotspots for targeted public health interventions, at-risk groups, and

to ultimately monitor and evaluate the effectiveness of the *National Decade* in the longer-term.

While our model continues to be key to informing decision-making around post-infectious diseases in Germany, eventually good real-world data should replace the need for stochastic modelling. The work of data collection to this end is beyond the scope of the *National Decade*, which underscores the importance of cross-agency collaboration and additional investment to improve outcomes and reduce costs around Long COVID and ME/CFS in Germany.

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