

## **Methodology: Investigate Europe patient group funding analysis**

The member companies of the European Federation of Pharmaceutical Industries and Associations (Efpia) have signed a code of ethics committing themselves to declare every year the payments made to:

- Healthcare Professionals (HCPs)
- Healthcare Organisations (HCOs)
- Patient Organisations (POs)

Investigate Europe's analysis on patient group funding is based on disclosures made in 2022 (the latest year of fully available data) by the 33 Efpia members to organisations in the EU, Norway, Switzerland and the UK.

### **Data collection**

The data collected primarily comes from disclosure documents published by the 33 Efpia members. These documents vary in content and style. Some pharmaceutical companies publish a global disclosure document, including payments made to groups in all countries. Others provide individual country PDFs or documents. Many companies do not. In such cases, data was collected from the individual national/regional websites of the pharmaceutical company as directed.

Disclosure data relating to patient groups in Belgium, France, the Netherlands, Portugal and Sweden is often not published by the pharmaceutical companies. In such cases, data must be accessed by the transparency registries operated by each country's national authorities.

### **Country cases**

The data accessible from national registries (Belgium, France, the Netherlands, Portugal and Sweden) is not consistent.

In Portugal, the national database is accessible but no differentiation is made about the type of body/individual which received money (e.g. healthcare organisations, patient organisations, doctor). Consequently data accessed from Portugal was filtered manually and the total is likely higher.

In the Netherlands, it is not possible to search the national database by company. Any searches of the registry must be done by name of patient organisation and their unique

organisation number. Consequently, it was not possible to interrogate the Netherlands database for payments made by the 33 members of Efpia. This means that payments made to groups in the Netherlands will likely be higher, as the data included in the analysis is only from documents published by the handful of pharmaceutical companies which provided information on the Netherlands.

In Belgium and France, the national databases can be filtered by patient organisation. However, no information about the purpose of the payments is provided.

### Patient organisation definition

The entities included in the analysis are either named in patient group disclosure documents created by pharmaceutical companies or from information accessed from national transparency registries (e.g. Belgium and France). They are organisations which the pharmaceutical companies themselves define as patient organisations.

In several cases, organisations informed Investigate Europe that they were not patient organisations but rather multi-stakeholder organisations or non-profits that have a broader remit. In these specific cases, the entities were removed from the analysis.

### Payments

In some instances, the totals disclosed by pharmaceutical companies are different to those published or shared by patient organisations. These are often explained due to the different accounting processes of companies and groups. In some cases, the totals listed in the disclosures are lower than figures provided by patient groups. For consistency, our analysis has maintained the amounts publicised in pharmaceutical company disclosures.

The majority of payments listed were given in euros. In cases where national currencies were used instead (e.g. GBP, SEK), all amounts were converted to euros using the 2022 average exchange rate as set by the European Central Bank. In cases where payments equate to the provision of products to a patient group, these donations have been removed from the analysis.

### Pharmaceutical companies

All 33 Efpia members were provided with information about payments which related to their companies. All were given the opportunity to provide any additional data in instances where no country payments could be found and the opportunity to clarify any

inaccuracies in their disclosure documents/data they gave to national authorities that the analysis is based on.