

# BMJ Open Industry funding of patient organisations in the UK: a retrospective study of commercial determinants, funding concentration and disease prevalence

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## ABSTRACT

**Objectives** To assess the relationship between UK-based patient organisation funding and companies' commercial interests in rare and non-rare diseases in 2020.

**Design** Retrospective analysis of the value and volume of payments from pharmaceutical companies to patient organisations in the UK matched with data on the conditions supported by patient organisations and drugs in companies' approved portfolios and research and development pipelines.

**Setting** UK.

**Participants** 74 pharmaceutical companies making payments to 341 UK-based patient organisations.

**Main outcome measures** Alignment between the commercial interests of pharmaceutical companies and the disease area focus of patient organisations; difference in the volume and value of payments to patient organisations broken down by prevalence of conditions; industry funding concentration, measured as the number of companies funding each patient organisation, the share of overall industry funding coming from each contributing company and the share of industry funding of each organisation comprised by the single highest payments.

**Results** 1422 payments were made by 74 companies to 341 patient organisations. Almost all funds (90%) from pharmaceutical companies were directed to patient organisations that are aligned with companies' approved drug portfolios and research and development pipelines. Despite rare diseases affecting less than 5% of the UK population, more than 20% of all payments were directed to patient organisations which target such conditions. Patient organisations focusing on rare diseases relied on payments from fewer companies (p value=0.0031) compared to organisations focusing on non-rare diseases.

**Conclusions** Companies predominantly funded patient organisations operating in therapeutic areas relevant to companies' portfolio or drug development pipeline. Patient organisations focusing on rare diseases received more funding relative to the number of patients affected by these conditions and relied more heavily on payments from fewer companies compared to organisations targeting non-rare diseases. Increased independence of patient organisations could help avoid conflicts of interest.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ We develop a methodology to determine the concordance between commercial interests of pharmaceutical companies and disease areas supported by patient organisations.
- ⇒ We present a comparative analysis of industry funding to patient organisations depending on the prevalence of the disease(s) they support.
- ⇒ Our analysis focuses on a recent time period which might differ from historical trends.

## INTRODUCTION

Patient organisations—not-for-profit organisations mainly composed of patients and/or caregivers that represent and support the needs of patients or caregivers<sup>1 2</sup>—play an important role in the development, regulatory review and adoption of new drugs.

During research and development, patient organisations effectively advocate for resources to be directed to conditions where unmet need is highest.<sup>3 4</sup> Patient organisations support research design and planning, helping to identify patient-relevant study endpoints.<sup>4</sup> Patient organisations also represent patient views and preferences at the time of regulatory review and health technology assessment of new drugs.<sup>5 6</sup> For example, during technology appraisals conducted by the National Institute for Health and Care Excellence (NICE), which makes funding recommendations for the English National Health Service, patients and organisations representing the interests of patients, provide testimonies of their first-hand experiences on how the disease affects them and those around them.<sup>7</sup> Finally, when drugs are launched, patient organisations contribute to dissemination of research results to patient

community and clinicians, and offer support and information on therapies available.<sup>4 8</sup>

Given the increasingly important role of patient organisations it is vital to understand their financial ties with pharmaceutical companies. Previous studies documented the large number and high value of payments from pharmaceutical companies to patient organisations,<sup>2 8–10</sup> the uneven distribution between and within therapeutic areas,<sup>2 10</sup> and the concentration of payments coming from a small number of pharmaceutical firms across multiple jurisdictions.<sup>2 8–16</sup>

What remains unknown is the alignment between the commercial interests of pharmaceutical companies and UK patient organisations' activities. Prior research has demonstrated that industry tends to prioritise commercially attractive conditions, and there is evidence to suggest that the marketing of a drug for a particular disease is associated with increased industry funding to patient organisations operating in that area.<sup>2 10</sup> However, such studies have typically been conducted in different geographical settings and have focused solely on marketed drugs, rather than examining the entire research and development pipeline of pharmaceutical companies. This is especially important given the lengthy timeline for drugs to reach the market,<sup>17</sup> as failure to consider drugs currently undergoing clinical trials may result in an incomplete picture.

Another gap in the literature relates to the dynamics between the pharmaceutical industry and patient organisations supporting rare versus non-rare conditions. In the UK, diseases are defined rare if they affect up to 5 people in 10 000.<sup>18 19</sup> The low prevalence of rare diseases and their different aetiology, coupled with the lack of interest from policymakers and manufacturers, who often prioritise more profitable and prevalent diseases, has necessitated the formation of patient organisations to advocate for the needs of rare disease patients.<sup>20 21</sup> The National Organisation for Rare Disorders, serves as the umbrella organisation for rare disease patients in the USA and has been instrumental in lobbying for scientific support and economic incentives to stimulate innovation in rare diseases.<sup>22</sup> This advocacy ultimately led to the passing of the Orphan Drug Act in 1983 in the USA and the European Union Regulation on Orphan Medicinal Products in Europe in 2000.<sup>18 23</sup>

Moreover, the limited availability and complexity of medical knowledge regarding rare diseases have also fostered patients and families affected by these conditions to come together to provide each other with support and medical expertise.<sup>20 24</sup> Patient organisations, which are primarily composed of patients and their caregivers, are in a unique position to share first-hand experiences that can inform research and regulatory decisions.<sup>25</sup> While this is true also for non-rare conditions, patient organisations' input in regulatory and health technology appraisals is particularly important in the context of rare diseases due to scarce evidence. For example, the Scottish Medicines Consortium provides opportunities for patient groups

and clinicians to have a stronger voice in the decision-making process for drugs used to treat rare and end-of-life conditions.<sup>26</sup> Similarly, three members of patient organisations sit in the Committee for Orphan Medicinal Products within the European Medicines Agency (EMA), the body responsible for granting orphan designations to drugs. Patient organisation-led registries that collect real-world data on disease progression can de-risk drug development for rare diseases.<sup>20</sup> While observational studies are common in non-rare diseases, they usually do not require the support of patient organisations' networks as patients are easier to identify and recruit.<sup>3</sup>

Finally, there has been limited exploration of the concentration of industry funding for patient organisations. A recent study by Mulinari and colleagues examined the average number of pharmaceutical companies making payments to Danish patient organisations,<sup>15</sup> while only one study has investigated the share of industry funding and the top drug company donor's share in UK patient organisations' income.<sup>11</sup> However, no study has specifically focused on the number of companies funding UK patient organisations, nor have they explored whether organisations' industry funding differs based on disease rarity.

Our paper aims to contribute to and expand on existing literature by examining the concordance between the commercial interests of pharmaceutical companies and patient organisations' activities in the UK. Using publicly available data on 2020 payments, we analysed the volume, value of payments to patient organisations according to their disease area of interest, with the objective of examining whether there are differences in funding patterns between rare and non-rare diseases. Lastly, we examined the concentration of industry funding, namely how many companies funded each patient organisation and the extent to which organisations might have been reliant on funding from a single company. Based on the reviewed literature, we formulated the following hypotheses:

*Hypothesis 1:* Regarding the concordance between the commercial interests of pharmaceutical companies and patient organisations' activities, we expect no difference between rare and non-rare patient organisations, under the assumption that companies are unlikely to fund organisations out of altruistic motives.

*Hypothesis 2:* Furthermore, we hypothesise that patient organisations targeting rare diseases would receive less overall funding due to their low prevalence. However, the existing incentives, high costs and consequent profitability of some orphan-designated drugs might affect the proportion of funding directed towards these organisations.<sup>27 28</sup>

*Hypothesis 3:* Considering the limited availability of drugs for rare diseases from a handful of manufacturers, we expect organisations focusing on these conditions to rely on payments of higher value and from fewer companies compared to those targeting more prevalent conditions.

## METHODS

### Data on industry payments

Disclosure reports on pharmaceutical companies' websites were our primary data source on payments from the pharmaceutical industry to UK patient organisations in 2020.<sup>29</sup> Disclosing payments to patient organisations is a requirement of Clause 29 of the Association of British Pharmaceutical Industry (ABPI) Code of Practice.<sup>30</sup> Specifically, the ABPI requires companies to keep a public record of any payment made to patient organisations on their website for a minimum of 3 years following the payment.<sup>30</sup> Companies that sign up to abide by the ABPI Code accept the jurisdiction of the Prescription Medicines Code of Practice Authority (PMCPA, code regulator), which also affects non-ABPI members operating in the UK.<sup>30</sup> Companies may be sanctioned by the PMCPA if they do not disclose their payments.<sup>30</sup> In an effort to increase transparency, Disclosure UK, an industry-led platform showing payments from pharmaceutical companies to healthcare professionals and organisations, launched a gateway in 2020 that collects hyperlinks to companies' disclosures of payments to patient organisations.<sup>31</sup>

First, we screened the websites of all pharmaceutical companies abiding by the ABPI Code, aided by the Disclosure UK patient organisations gateway. We retrieved payments information from the companies' websites to ensure that all payments were captured. Second, in light of a recent study unveiling that payments to patient organisations were misreported in the Disclosure UK database of payments to healthcare organisations (HCOs),<sup>16</sup> we screened the 2020 Disclosure UK HCOs database for payments to patient organisations.

If payments were not disclosed in the company's website nor in the Disclosure UK HCOs database, we assumed that the company did not make any payments to patient organisations in 2020, as commonly assumed in the literature.<sup>2</sup>

One investigator (AG) extracted payment disclosures from the companies' websites. These comprised the name of the patient organisation, the year when the payment was made, the reason for the payment and its value in the currency reported by the disclosing company. The 2020 Disclosure UK HCOs database was also screened, and recipients were matched to standardised patient organisations names. To ensure the data's accuracy, the final database was scanned for duplicates, but no such instances were found. When reported in different currencies, such as United States dollars, Swiss franc, Swedish krona, Norwegian krone and Danish krone, the value of the payment was converted to Great British pounds (GBP), using the Office of National Statistics historical yearly conversion rates.<sup>32 33</sup> All payments are reported in 2020 GBP. Two in-kind payments with a monetary value of zero were excluded from the analysis. Further details on variables' cleaning and coding can be found in the online supplemental material.

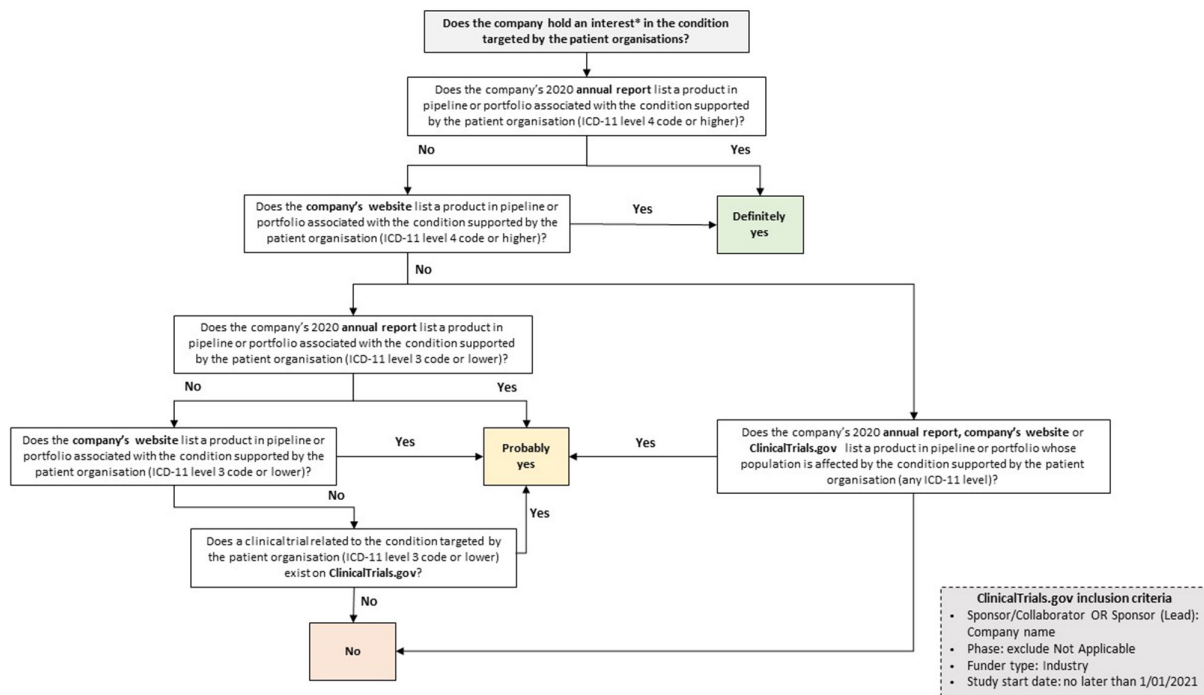
### Data on patient organisations

We retrieved data on patient organisations from their websites. Details on the therapeutic area they advocated for—proxied by International Classification of Diseases V.11 (ICD-11) codes—and whether the condition(s) was rare or non-rare were also extracted. Conditions were considered rare if they appeared in the Orphanet database of rare diseases,<sup>34</sup> which is the platform and repository of data on rare diseases and orphan drugs. Patient organisations that did not match the European Federation of Pharmaceutical Industries and Associations (EFPIA) definition of what constitutes a patient organisation were excluded from the analysis. We chose the EFPIA's definition for the following reasons. First, this corresponds the definition used in the wider peer-reviewed literature.<sup>2 35</sup> Second, other commonly used definitions, such as the one from the EMA, refer to the structure of patient organisations' governing bodies, which have to consist of over 50% patients.<sup>36</sup> Considering the high number of patient organisations included in our analysis, this requirement was challenging—if not impossible—to verify. Second, EFPIA's definition indicates what the pharmaceutical industry considers to be a patient organisation. Therefore, it helped us minimise selection bias issues as it includes a wide range of organisations. We excluded 66 payments to patient organisations that did not match EFPIA's definition. Subgroup analyses on excluded organisations can be found in the Online supplemental material.

### Determining commercial interests

We assessed whether—and the extent to which—a pharmaceutical company holds an interest in the disease supported by a patient organisation. We adapted the definition of 'interest' provided by NICE.<sup>37</sup> An interest is when there is, or could be perceived to be, an opportunity for a pharmaceutical company to benefit in the disease area where the patient organisation operates. This could include cases where the pharmaceutical company has a drug developed or in development for a condition targeted by the patient organisation, or where a drug in the company's portfolio or pipeline is restricted to a specific population affected by the disease supported by the patient organisation. We define portfolio as a group of drugs that a pharmaceutical company has already developed, gained regulatory approval for and is actively marketing or selling. Conversely, pipeline refers to the collection of drug candidates being developed by a pharmaceutical company, at various stages of development, from preclinical research to clinical trials.

To establish whether an interest existed or not, we first classified the conditions targeted by patient organisations to ICD-11 codes using the online ICD-11 database.<sup>38</sup> ICD-11 codes are mutually exclusive, exhaustive and are arranged as a single hierarchical tree, from level one (most general eg, *neoplasms*) to five (most specific eg, *plasma cell myeloma*). This means that specific diseases are nested within broader classifications. Although some



**Figure 1** Classification model to determine company interests in patient organisation funding. Note: An interest is when there is, or could be perceived to be, an opportunity for a pharmaceutical company to benefit in the disease area where the patient organisation operates. ICD-11, International Classification of Diseases V.11.

patient organisations, such as hospital charities, carers organisations and hospices, could not be matched to specific ICD-11 codes, they were included in the analysis to provide a comprehensive overview. As a result, the analysis presented results for both disease-specific and non-disease-specific organisations.

We then searched companies' annual reports, websites and the ClinicalTrials.gov registry to determine whether each company had an interest in the condition targeted by the patient organisation receiving the payment. Figure 1 schematically illustrates the approach taken to understand whether—and the degree to which—a company has an interest in the conditions (*definitely yes*, *probably yes*, *no*). For example, if *Company X* declares in its annual report having a drug in development for multiple myeloma and made a payment to *Blood Cancer UK*, this would be coded as *probably yes*, as the company has a product in its pipeline or portfolio nested within a broader class of conditions targeted by the patient organisation. Conversely, should *Company X* have made a payment to *Myeloma UK*, this would have been coded as *definitely yes*, as there is perfect alignment between the condition targeted by the patient organisation and by *Company X's* drug. Cases in which a company's interest in a certain condition could not be identified were coded as *no*. However, these instances might be due to limitations in data availability and therefore do not necessarily indicate that there was no company interest. Data on pharmaceutical companies' portfolio and pipeline were retrieved from their latest annual reports, company websites and ClinicalTrials.gov.<sup>39</sup>

One investigator (AG) initially coded all data, while the other (IP) blindly re-coded a 30% random sample of payments to validate the data collection process and minimise the risk of reporting errors. We followed this process when validating all data sources described above. Any disagreement was discussed until consensus was reached.

### Analysis of industry funding concentration

We assessed the concentration of industry funding received by patient organisations. In a prior study, Ozieranski and colleagues examined funding disparities among HCOs in the UK in 2015, using the Gini coefficient to assess the distribution of funding.<sup>40</sup> However, the authors acknowledged that the data preparation process presented challenges, limiting the analysis to payments from a single year. While this methodology has its advantages, we found that the time-consuming process of reshaping the data outweighed the benefits over using descriptive statistics. In particular, we calculated (1) the number of companies funding each patient organisation, (2) the share of overall industry funding to each patient organisation coming from each contributing company and (3) the share of industry funding of each organisation comprised by the single highest payment.

The Online supplemental material provides further details on the data collection and how the outcomes were constructed. Descriptive statistics and tests, such as ranges and Mann-Whitney U tests, were presented in the analysis. These statistics were preferred over the mean due to the skewed distribution of the data analysed. All analyses

and data visualisations were performed using Stata V.17 and RStudio (*ggplot2* package), respectively.

### Patient and public involvement

Patients were not involved in this study as our analyses focused on patient organisations as institutional actors rather than single patients with specific conditions. We plan to disseminate key findings from our analysis to patients and members of the public.

## RESULTS

In 2020, 74 companies made 1422 payments to 341 patient organisations, amounting to £22.6million. Out of the total of 1422 payments made by pharmaceutical companies to patient organisations in 2020, 82% (1168 payments) with a value of £18million were accurately disclosed on the companies' websites. The remaining 18% (254 payments) with a value of £4.6million were reported in the Disclosure UK HCOs database. Among the companies, 24 out of 74 reported payments only on their websites, while 14 reported payments only in the Disclosure UK HCOs database and 36 reported payments in both.

Overall, *diseases of the nervous system* (£4.3million) was the most funded therapeutic area over time, followed by *neoplasms* (£3.2million) and *endocrine, nutritional or metabolic diseases* (£3.4million). The conditions that received more funding in 2020 were multiple sclerosis (£1.7million), followed by obesity (£1.4million) and epilepsy (£1million). Pfizer, Novo Nordisk, UCB, Novartis and Roche were the top five funders over the study period (figure 2). These companies contributed to more than one-third (36%) of all payments.

Table 1 summarises the number and value of payments to patient organisations.

### Companies' interest in payments to patient organisations

In 2020, 85% of all payments were directed to patient organisations that were judged to be aligned with their portfolio or pipeline. Only 15% of payments were made to organisations that focused on conditions that could not be linked to a product in the funder's portfolio or pipeline. Table 2 shows the volume and value of payments, broken down by the company's interest variable, overall and whether patient organisations targeted a rare or non-rare disease. Payments to patient organisations targeting a disease for which the company has a product developed or in development (*definitely yes*) made up 56% and 54% for patient organisations targeting rare and non-rare conditions, respectively. However, this difference was not statistically significant as anticipated in *Hypothesis 1* ( $\chi^2 = 1.049$ ,  $p$  value=0.592).

The monetary value of payments coded as *definitely yes* accounted for 55% of the overall payment value. However, this was as high as 67% for patient organisations targeting rare diseases, versus 59% for organisations focusing on non-rare conditions. This difference was found to be

statistically significant ( $\chi^2 = 370.163$ ,  $p$  value=0.058). When payments coded as *probably yes* were included, the share increased to 90% and 97% for all patient organisations and disease-specific organisations only, respectively.

### Industry funding of patient organisations focusing on rare versus non-rare conditions

Of the £22.6million in payments from industry to patient organisations, £4.6million (21%;  $n=286$ ) were directed to organisations focusing on rare diseases while £15.9million (70%;  $n=952$ ) to organisations supporting non-rare conditions. The remaining 9% was directed to non-disease-specific patient organisations, which were excluded from this analysis. Linking these results to *Hypothesis 2*, we observe that patient organisations supporting rare diseases received less but still substantial funding.

The most funded patient organisation overall in 2020 was the European Association for the Study of Obesity, receiving almost £1.5million, followed by Epilepsy Society (£955 600) and Shift.MS (£588 451). Among the top 10 recipients overall in 2020, only one focused on rare diseases (Cystic Fibrosis Trust). However, it is worth noting that Blood Cancer UK, which focuses on malignant haematological malignancies including rare cancers, ranked seventh on the list.<sup>41</sup> The Cystic Fibrosis Trust (£445 229), The Society for Mucopolysaccharide Diseases (£358 037) and the International Patient Organisation for Primary Immunodeficiencies (£345 914) were the top three recipients focusing on rare diseases, followed by Myeloma UK with a slightly lower amount (£340 604).

Figure 3 shows therapeutic areas in order from most to least funded, broken down by rarity of disease targeted. In the case of organisations focusing on rare diseases, endocrine, nutritional or metabolic disease, neoplasms and diseases of the nervous system received most funds. Together, the top three most funded disease areas represented about half of overall funding (57%). When looking at the non-rare conditions that attracted most funding, multiple sclerosis was first (£1.7million), followed by diabetes (£1.4million) and epilepsy (£1million). Cystic fibrosis, primary immunodeficiencies and lysosomal storage diseases, which include rare metabolic disorders such as Fabry and Gaucher diseases, received the highest funding overall, attracting £445 229, £363 998 and £358 037, respectively.

### Industry funding concentration

Each patient organisation received payments from a median of approximately one unique company, with 1 (IQR: 1–2) and 2 (IQR: 1–3) companies funding patient organisations targeting rare and non-rare diseases, respectively. However, this difference was not statistically significant ( $z=1.582$ ,  $p$  value=0.114). Overall, the range of unique companies making payments to a unique patient organisation spanned from a minimum of 1 to a maximum of 13. The latter was recorded for Genetic Alliance UK, a national charity and an alliance of over 200



**Table 1** Number and value of payments from the pharmaceutical industry to UK patient organisations broken down by year and rarity of diseases

Payment statistics	
Number of payments	1422
Median payment (IQR; overall)	£7943 (£1200–£15 000)
Median payment (IQR; rare)	£8775 (£2500–£15 965)
Median payment (IQR; non-rare)	£9060 (£1520–£16 850)
Value of payments (£; overall)	£22 577 314
Value of payments (£; rare)	£4 629 779
Value of payments (£; non-rare)	£15 875 662
Number of pharmaceutical companies	74
Number of patient organisations	341

Notes: All payments are expressed in 2020 Great British pounds. The supplemental materials detail the conversion rates used, which were retrieved from the Office of National Statistics website. Further details on how patient organisation data were cleaned and coded, please see the online supplemental materials. Please note that the number of pharmaceutical companies and patient organisations making and receiving payments across the study period refers to companies and organisations that made or received at least one payment, respectively.

patient organisations, supporting those affected by rare genetic conditions.

In our sample, the median yearly payment of a company to a patient organisation comprised 24% of its overall industry payments (IQR: 9.5%–74%). When looking at patient organisations focusing on rare diseases, the median company contribution was as high as 30% (IQR: 11.6%–93%) versus 23% (IQR: 9.4%–65.8%) for non-rare conditions ( $z=-2.164$ ,  $p$  value=0.031).

Finally, the share of industry funding comprised of the single highest payment per organisation amounted to an average of 67.5% (SD: 0.30) for all years, ranging from a minimum of 8.5% to a maximum of 100%. The highest value payment in the case of patient organisations targeting rare diseases made up a larger share of the overall industry funding (median: 71%, IQR: 43.5%–100%), despite not significant, compared with those focusing on more prevalent conditions (median: 62.5%, IQR: 34.7%–100%). While there was not a significant difference in the number of funding companies between patient organisations supporting rare and non-rare diseases ( $z=-1.087$ ,  $p$  value=0.277) as stated in *Hypothesis 3*, the former relied on larger payments. Histograms illustrating the distribution of the statistics explored in this analysis can be found in the online supplemental materials.

## DISCUSSION

In this study, we evaluated the financial links between the pharmaceutical industry and patient organisations in the UK in 2020. This is the first study to document the almost-perfect concordance of pharmaceutical company

**Table 2** Volume and value of payments by company interests in 2020

PO type	Company's interest	Volume; n	
		(%)	Value: £
Overall*	Definitely yes	678 (48)	£12 529 514 (56%)
	Probably yes	525 (37)	£7 700 069 (34%)
	No†	219 (15)	£2 347 732 (10%)
Rare	Definitely yes	161 (56)	£3 119 217 (67%)
	Probably yes	115 (40)	£1 388 545 (30%)
	No†	10 (4)	£122 017 (3%)
Non-rare	Definitely yes	517 (54)	£9 410 297 (59%)
	Probably yes	389 (41)	£6 056 915 (38%)
	No†	46 (5)	£408 449 (3%)

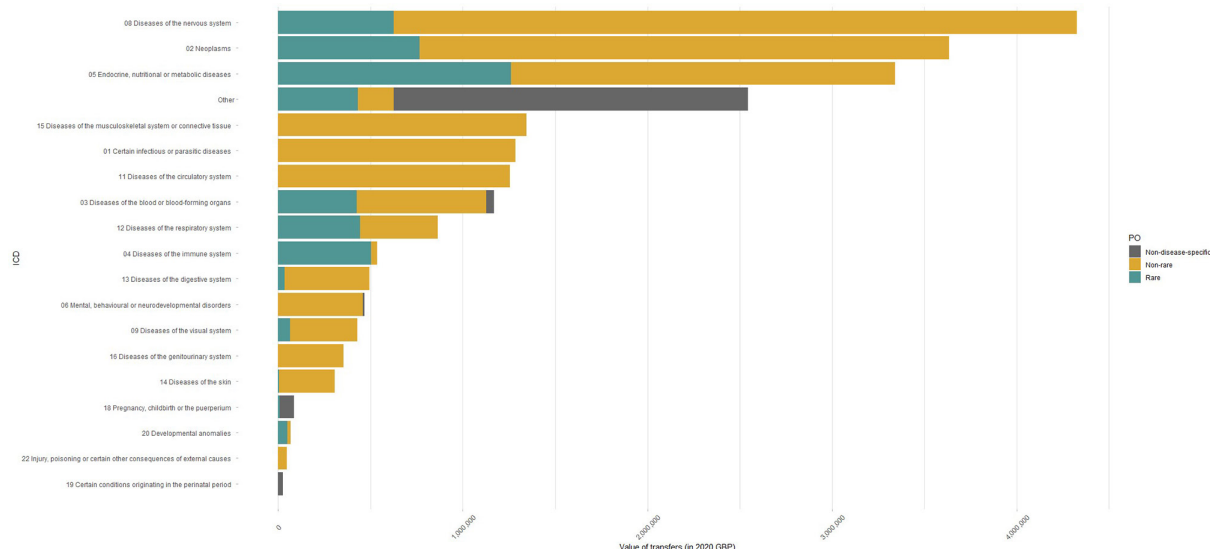
Notes: *Definitely yes* indicates payments directed to patient organisations that operated in a disease area (ICD-11 level 4 or higher) for which the company has a product in its portfolio or pipeline. *Probably yes* indicates directed to patient organisations that operated in a disease area (ICD-11 level 3 or lower) for which the company has a product in its portfolio or pipeline. *No* refers to directed to patient organisations that operated in a disease area for which no link could be found to the company's portfolio or pipeline. The higher the ICD-11, the more specific the condition. For example, if the ICD-11 level 4 is *plasma cell neoplasms*, level 2 would be *neoplasms of haematopoietic or lymphoid tissues*. Further details on how this variable was constructed can be found in the online supplemental material

\*Please note that the *overall* results are not a sum of the *rare* and *non-rare* results, as they also include patient organisations that could not be classified in either group and are non-disease-specific.

†Please note that the *no* category of interest conservatively includes also interests that were considered as unclear. ICD-11, International Classification of Diseases V.11; PO, patient organisations.

interests and patient organisation funding in the UK. Almost all industry payments during our study period—in terms of both volume (85%) and value (90%)—were to patient organisations aligned with pharmaceutical companies' portfolios and pipelines. This share was even higher when considering only disease-specific patient organisations (97%). Despite rare diseases affecting less than 5% of the UK population, more than 20% of industry funding to patient organisations in 2020 was directed towards organisations focusing on such conditions (£4.6million/£22.6million). Finally, we found that patient organisations targeting rare diseases relied on payments from fewer companies but of higher value compared with organisations focusing on non-rare diseases.

The almost-perfect concordance between industry interests and patient organisation activities likely reflect the commercial attractiveness of conditions targeted by pharmaceutical companies.<sup>2 42</sup> Such close alignment between the interests of companies and patient organisations might undermine the credibility of patient organisations as perceived by the general public and might raise questions about patient organisations' inputs in regulatory



**Figure 3** Cumulative value of payments by patient organisation type and therapeutic area from in 2020. Note: Non-disease-specific patient organisations include organisations that could not be matched to specific International Classification of Diseases V.11 codes or could not be classified as rare or non-rare, such as hospital charities, carers organisations and hospices. GBP, Great British pounds.

and health technology appraisals.<sup>9 43 44</sup> Similarly, a study found that during NICE appraisal meetings fewer than 25% of all relevant financial ties between patient organisations and pharmaceutical companies were disclosed.<sup>45</sup> As discussed by the Mandeville and colleagues, this lack of transparency increases the risk of conflicts of interest not being properly detected and managed.

Our findings make an important contribution to the existing body of literature on industry funding of patient organisations. Ozieranski *et al* found that industry donated over £57 million to UK patient organisations from 2012 to 2016, an average of £11.5 million per year.<sup>2</sup> The authors also observed that payments were concentrated in commercially attractive therapeutic areas, with organisations focusing on cancer receiving more than 36% of overall payments.<sup>2</sup> However, the study did not examine whether companies were more likely to fund organisations that target diseases for which they have already developed or are currently developing products. Another earlier study examined payments to Swedish patient organisations and found an association between drug commercialisation and industry funding.<sup>10</sup> The authors did not take into account products in the companies' pipelines nor drugs that might have not yet launched in Sweden. Considering that patient organisations have an important role not only in the post-commercialisation phase but also in the R&D and approval stages. We therefore developed a replicable classification model to determine whether payments from companies were directed at organisations that were aligned with their portfolios and pipelines.

Patient organisations focusing on rare diseases can drive both supply of and demand for medicinal products due to their research, advocacy and education role.<sup>4 46</sup> As a result of their close ties with patients, these organisations

have the credibility and power to educate patient communities, advocate for access to available therapies and raise awareness on the unmet need of certain conditions.<sup>4 20 47</sup> Although a large share of both the value and number of payments were directed to patient organisations focusing on rare diseases, most funds targeted commercially attractive rare conditions, such as multiple myeloma and cystic fibrosis, where the unmet need is relatively low compared with other rare conditions. These are diseases that have relatively high prevalence and for which 10 and 29 treatments, respectively, are currently approved for use in Europe.<sup>34 48</sup> Furthermore, rare diseases have proved a lucrative asset for pharmaceutical companies.<sup>42</sup> The additional market protection granted to orphan-designated product and the often higher willingness to pay from payers has led companies to increasingly focus on these medicines, which can offer a high return on investment.<sup>27 28</sup> This poses the risk of widening already existing health inequities, where severe and debilitating rare conditions that affect a small number of patients do not receive the resources they need and have to rely on limited public grants.<sup>49</sup>

Finally, our analysis showed that patient organisations focusing on rare diseases are funded by very few companies, relying on a single payment for over 70% of their industry-reported income. Despite the share of industry contributions among the overall patient organisation's income was found to be low in the literature,<sup>11</sup> this increases the risk of pursuing the company's commercial interests rather than objectively representing a patient body.<sup>12</sup> In this study we find that patient organisation received payments from a median of approximately one unique company (IQR: 1–3), ranging from 1 to a maximum of 13. This corresponds to an average of 2.6 (SD: 2.3) funding companies per patient organisation.



This is consistent with findings from a recent study investigating the distribution of payments from industry to Danish patient organisations, which found that on average, most organisations were funded by 2.6 (SD: 2.1) on average.<sup>15</sup>

These findings have important implications for policy and practice. To minimise conflicts of interests and maintain the integrity of patient organisations, particular attention should be paid to funding from companies in the period before or after a patient organisation has endorsed this company's product.<sup>45</sup> However, the duration of this period should be carefully evaluated to avoid overlooking more historical commercial ties.<sup>50</sup> One way of avoiding potential conflicts of interest is through increased transparency. Despite considerable progress on this front, especially in terms of reporting the monetary value of industry payments, there are still gaps in reporting.<sup>51</sup>

As highlighted in this and other studies, several companies misreport their payments to patient organisations.<sup>16</sup> Our study found that only 32% of companies disclose all of their payments correctly (ie, on their website), while the rest report them on both their websites and the Disclosure UK HCOs database (49%) or solely on the latter (19%). This duplication of reporting efforts makes it harder to achieve transparency and obtain a comprehensive overview of the financial relationships between companies and patient organisations. Therefore, efforts should be made to establish a unique repository for payments to patient organisations, similar to the one currently in place for physicians and HCOs.

Furthermore, the financial independence of patient organisations is fundamental to ensure that patients' interests are at the forefront of the organisations' agenda.<sup>52</sup> Compromising this independence can have a detrimental effect and distort public health priorities. For example, AbbVie-sponsored patient organisations were found to strongly oppose switching to biosimilars for HUMIRA, the company's blockbuster drug, in various countries.<sup>15</sup> Similarly, a recent investigation uncovered strong financial connections between Novo Nordisk and UK-based patient organisations that supported the approval of the company's latest obesity drug. This, alongside other ongoing investigations, culminated in the suspension of the company from ABPI.<sup>53</sup> The strong financial ties between Novo Nordisk and patient organisations, contributing to the NICE appraisal of the company's drug, raises serious concerns about these groups' independence and might ultimately harm patients.<sup>50</sup> Notably, our analysis found Novo Nordisk to be the second highest funder of patient organisations in term of value in 2020 for an amount of more than £1.8million. In the long-term, policymakers should make sure that patient organisations receive adequate public funding regardless of whether they focus on conditions that are profitable for the industry. Such public funding is particularly important for patient organisations supporting rare diseases, as relatively few companies have financial links with patient organisations

focusing on rare diseases, potentially creating high reliance on few high-value payments.

This study had limitations. First, the lack of mandatory reporting of payments to patient organisations by companies that do not comply with the ABPI Code is a major limitation of our analysis.<sup>54</sup> For example, our data set does not include payments by Vertex, a company with a rare-focused portfolio and a strong presence in cystic fibrosis.<sup>55</sup> Even for companies that are signatories of the ABPI Code, under-reporting of payments to patient organisations and removal of disclosure reports from the public domain has been observed.<sup>13 56 57</sup> Second, in our assessment of company interests, we made a conservative assumption that only patient organisations which target relatively narrow conditions were eligible to be coded as *definitely yes*. Despite this assumption, we concluded that more than half of payments were in therapeutic areas in which companies had a clear interest. Finally, our analysis focused on a recent though limited time period. While previous publications show similar trends in terms of the most funded diseases and absolute value of payments,<sup>2 10</sup> lending credibility to our analysis and underlying data, it is still unclear whether these trends hold over time and their generalisability to other periods.

There are several avenues which can be explored further to build on this analysis. While some of the previous literature on the topic has focused on the financial dependency of patient organisations' budgets from pharmaceutical funding,<sup>11</sup> whether this differs depending on the rarity of the disease targeted has not been explored. Due to the small number of patients affected by rare conditions, patient organisations that target such conditions may be less well-equipped to finance their activities via charitable events and may rely more heavily on contributions from pharmaceutical companies. Lastly, while our analysis did not evaluate the effect of COVID-19 on the financial dynamics between pharmaceutical companies and patient organisations, we expect that the pandemic had a substantial effect on the type, value and distribution of payments. Future research should examine the impact of COVID-19 on industry funding of patient organisations.

## CONCLUSIONS

Almost all industry funding of UK patient organisations in 2020 was in areas that were aligned with companies' approved drug portfolios and research and development pipelines. Pharmaceutical companies spent a larger amount on patient organisations focusing on rare diseases and these organisations relied on a small of companies for their funding.

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## 1 Supplemental Material

### 2 Data collection

#### 3 Payments

4 We retrieved data on 2020 payments from pharmaceutical companies to patient organisations  
5 from the following sources:

- 6 1) **Companies' websites**. Disclosing payments to patient organisations is a requirement  
7 of Clause 29 of the Association of British Pharmaceutical Industry (ABPI) Code of  
8 Practice.<sup>1</sup> Specifically, the ABPI requires companies to keep a public record of any  
9 payment made to patient organisations on their website for a minimum of three years  
10 following the payment.<sup>1</sup> Therefore, companies' website were our primary data source  
11 on payments to patient organisations.
- 12 2) **Disclosure UK HCOs database**. In light of a recent study unveiling that payments to  
13 patient organisations were misreported in the Disclosure UK database of payments to  
14 healthcare organisations (HCOs),<sup>2</sup> we also screened the 2020 Disclosure UK HCOs  
15 database for payments to patient organisations.

16 If payments were not disclosed in the company's website nor in the Disclosure UK HCOs  
17 database, we assumed that the company did not make any payments to patient organisations in  
18 2020, as commonly assumed in the literature.<sup>3</sup>

19 One investigator (AG) extracted payment disclosures from the companies' websites. These  
20 comprised the name of the patient organisation, the year when the payment was made, the  
21 reason for the payment and its value in the currency reported by the disclosing company. The  
22 2020 Disclosure UK HCOs database was also screened, and recipients were matched to  
23 standardised patient organisations names. To ensure the data's accuracy, the final database was  
24 scanned for duplicates, but no such instances were found. When reported in different  
25 currencies, such as United States Dollars (USD), Swiss Franc (CHF), Swedish Krona (SEK),  
26 Norwegian Krone (NKK) and Danish Krone (DKK), the value of the payment was converted  
27 to Great British Pounds (GBP), using the ONS historical yearly conversion rates.<sup>4 5</sup> Two in-  
28 kind payments with a monetary value of zero were excluded from the analysis. Further details  
29 on variables' cleaning and coding can be found in the Supplemental Material.

#### 30 **Therapeutic areas**

31 Patient organisations' websites were also screened to understand the condition(s) they focused  
32 on. For example, in the case of *Blood Cancer UK*, their mission is to "*beat blood cancer*",  
33 therefore, the condition supported was coded as blood cancer.

34 After being identified as described above, conditions were further classified into rare and non-  
35 rare.

1 Conditions were considered rare if they appeared in the Orphanet database of rare diseases  
 2 regardless of their classification level (group of disorders, disorders or subtypes of disorders).<sup>6</sup>  
 3 For example, multiple myeloma appears in the Orphanet database of rare diseases, therefore a  
 4 patient organisation focusing this condition would be categorised as rare-focused. When  
 5 condition sub-types appeared in the Orphanet database, the patient organisation's website was  
 6 screened to check whether its focus was on rare conditions. For example, *Metabolic Support*  
 7 *UK's* motto is "Your rare condition. Our common fight" and was therefore assumed to be rare  
 8 disease-focused. Conversely, should a patient organisation focus on a broader condition such  
 9 as blood cancer with no sole focus on rare conditions, the organisation would be conservatively  
 10 considered non-rare. While this approach was preferred as it did not require further  
 11 assumptions, it entails that only more specialised patient organisation are considered as rare.  
 12 Such approach might have led to the number and overall value of payments from  
 13 pharmaceutical companies to rare diseases-focused patient organisations being underestimated,  
 14 as these organisations are expected to get less payments than more generalist ones (e.g. multiple  
 15 myeloma vs blood cancer).

16 A third category (*unclear*) was created for non-disease-specific patient organisations, such as  
 17 coalition of charities or organisations focused on palliative care for terminally ill patients. This  
 18 category was excluded from the main analyses, but sub-group analyses are reported at the end  
 19 of the Supplemental Material.

## 20 **Companies' interest**

21 We developed a methodology to assess the extent to which a pharmaceutical company holds  
 22 an interest in the disease supported by a patient organisation. For the purpose of this analysis,  
 23 we adapted the definition of interest provided by NICE.<sup>7</sup> An interest is when there is, or could  
 24 be perceived to be, an opportunity for a pharmaceutical company to benefit in the disease area  
 25 where the patient organisation operates. This could include situations where the pharmaceutical  
 26 company has a drug developed or in development for a condition supported by the patient  
 27 organisation, or where a drug in the company's portfolio or pipeline is restricted to a specific  
 28 population affected by the disease supported by the patient organisation.

29 As first step, the conditions supported by patient organisations were translated into ICD-11  
 30 codes using the online ICD-11 database.<sup>8</sup>

31 ICD-11 codes are mutually exclusive, exhaustive and are arranged as a single hierarchical tree.  
 32 This means that specific diseases are nested within broader classifications. An example for  
 33 multiple myeloma is shown in Table 1 below.

34

35 **Table 1. Example of ICD-11 classification, Multiple myeloma**

Hierarchy level	Condition	ICD-11 code
Level 1	Neoplasms	2
Level 2	Neoplasms of haematopoietic or lymphoid tissues	2A
Level 3	Mature B-cell neoplasms	2A8
Level 4	Plasma cell neoplasms	2A83
Level 5	Plasma cell myeloma	2A83.1

1

2 In this example, multiple myeloma is nested within *Plasma cell myeloma*, who is in its turn  
3 nested within *Plasma cell neoplasms* and so on up to *Neoplasms*.

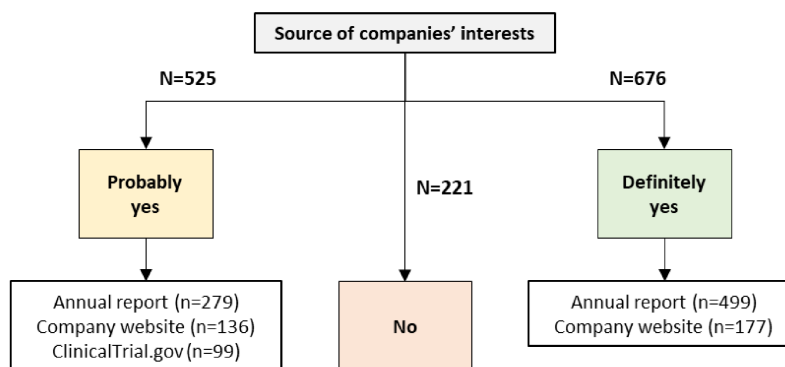
4 Subsequently, companies' annual reports, website and the ClinicalTrials.gov database were  
5 searched to assess whether the each company had an interest in the condition supported by the  
6 patient organisation receiving the payment. The diagram in the main document (Figure 1)  
7 schematically illustrates the approach taken to understand whether the company definitely,  
8 probably or did not have an interest in the condition. Figure 1 below illustrates the source of  
9 companies' interests.

10 For example, if *Company X* reports in its annual report having a drug in development for  
11 multiple myeloma and transferred a sum of money to *Blood Cancer UK*, this would be coded  
12 as *probably yes*, as the company has a product in its pipeline or portfolio associated with a  
13 condition supported by the patient organisation. In this case, the ICD-11 level would be 2,  
14 *Neoplasms of haematopoietic or lymphoid tissue*, under which multiple myeloma is nested.  
15 Conversely, should *Company X* have made a payment to *Myeloma UK*, this would have been  
16 coded as *definitely yes*, as there is perfect alignment between the condition supported by the  
17 patient organisation and by *Company X's* drug.

18 Situations where a company's interest in a certain condition could not be identified indicate an  
19 impossibility of identifying such link, rather than the lack thereof.

20

21 **Figure 1. Source of companies interests**



22

23

## 1 Variables cleaning and coding

## 2 Table 2. Description of key variables in payment database

Variables name	Description	Details
<b>Company</b>	Standardised company name	Company name as reported on company website and/or on HCOs database. Two mergers involving companies included in our analysis—BMS and Celgene, and Takeda and Shire—were completed prior to 2020. Although these companies had merged, we treated them as separate entities because their disclosures were reported separately even after the acquisition.
<b>ABPI member</b>	ABPI membership of company; <i>source: <a href="#">ABPI full members list</a></i>	0 = not ABPI member, 1 = ABPI member
<b>Company_condition</b>	Concatenation of company name and disease area targeted by the patient organisation	Concatenation used for coding and analysis purposes
<b>Company interest</b>	Whether the company hold an interest* in the condition targeted by the patient organisation	<ul style="list-style-type: none"> <li>- <b>Definitely yes:</b> the company's annual report or website list a product for the condition targeted by the patient organisation in its portfolio/pipeline (ICD-11 level 4 or above)</li> <li>- <b>Probably yes:</b> the company's annual report or website list a product for the condition targeted by the patient organisation in its portfolio/pipeline OR a clinical trial for which the company is sponsor is listed for the disease targeted by the patient organisation OR a drug in the company's pipeline/portfolio is restricted to a specific population affected by the disease targeted by the patient organisation (ICD-11 level 3 or below)</li> <li>- <b>No :</b> None of the above</li> </ul>
<b>Source</b>	Source of company interest variable	Annual report, company website, ClinicalTrials.gov, none
<b>Name of PO</b>	Name of patient organization as reported by companies in disclosure report	-
<b>Standardised PO name</b>	Standardised name of patient organization to avoid duplicates and inconsistencies	For coding purposes, names of patient organisations were standardised. The following steps were taken: <ol style="list-style-type: none"> <li>1. Patient organisations' names for typos, abbreviations, spelling mistakes and duplicated within the companies' disclosures (e.g. Crohn's &amp; Colitis UK and CCUK would both be standardized to Crohn's and Colitis UK);</li> <li>2. If the patient organisation changed name over time, the latest name on record was used;</li> </ol>

		<ol style="list-style-type: none"> <li>3. If the two patient organisations merged over the study period, the name of the merged entity was used (e.g. the British Lung Foundation and Asthma UK merged into Asthma + Lung UK);</li> <li>4. Separate entries were made for patient organisations under the same umbrella but focusing on different geographical entities (e.g. Alzheimer UK vs Alzheimer Scotland)</li> </ol>
<b>Reason for exclusion</b>	Reason why the organisation was excluded from the analysis	<ul style="list-style-type: none"> <li>- Not UK organisation (not aligned with geographical scope e.g. Irish, US-based);</li> <li>- For profit company (not aligned with definition of patient organization used in the study);</li> <li>- Missing information (organisations for whose nature is unclear i.e. patient organisation website could not be identified)</li> </ul>
<b>ICD-11</b>	Classification of disease targeted by the patient organisation according to the WHO ICD-11; <i>source: <a href="#">ICD WHO website</a></i>	General classification (ICD-11 chapters) <i>See Excel file, Inputs tab</i>
<b>Condition</b>	Condition targeted by patient organisation as reported on website	e.g. Blood Cancer UK would fall under ICD-11 code 02 Neoplasms, with <i>blood cancer</i> being the condition
<b>Charity number (if any)</b>	Charity number as reported in the organization website or as reported in the <a href="#">England and Wales Charity Commission website</a>	When both England/Wales and Scotland or Northern Ireland charity numbers were provided, the former was chosen. Scotland and Northern Ireland charity numbers were reported only when those for England/Wales were missing
<b>Company number (if charity number missing)</b>	Company number as reported in the organization website or as reported in the <a href="#">Government Company Information Service website</a> if the patient organization cannot be found in the charity commission database (e.g. limited by guarantee company)	When both England/Wales and Scotland or Northern Ireland charity numbers were provided, the former was chosen. Scotland and Northern Ireland charity numbers were reported only when those for England/Wales were missing
<b>Link</b>	Link of patient organisation website	-
<b>Rare disease</b>	Whether the condition or one of the conditions targeted by the patient organisation is considered as rare	<p>A condition was considered as rare if it under at least one of the following criteria:</p> <ol style="list-style-type: none"> <li>1. The condition is listed in <a href="#">Orphanet list of rare diseases</a> regardless of its ICD-11 level classification;</li> <li>2. In their website, the patient organisation explicitly describe the disease they target as rare (e.g. <i>Metabolic Support UK's</i> motto is “<i>Your rare condition. Our common fight</i>” and was therefore assumed to be rare disease-focused)</li> </ol>



<b>Details of payment</b>	Details of payment as reported by companies in disclosure report	-
<b>Country</b>	Country of payment	The country considered for the entire database is the UK
<b>Year</b>	Year of payment	2020
<b>Currency</b>	Currency of payment	Currency the payment is reported in the disclosure reports (i.e. EUR, GBP, USD, CHF, SEK, NKK)
<b>Currency_year</b>	Concatenation of currency and year of payment for conversion purposes	-
<b>Value of payment</b>	Value of payment in original currency as reported by companies in disclosure report	In-kind payments were removed from the analysis as no monetary value could be associated to such payments
<b>Value in 2020 pounds</b>	GBP converted value of payment	See details in <i>Inputs</i> sheet

1 \*An interest is when there is, or could be perceived to be, an opportunity for a pharmaceutical company to  
2 benefit in the disease area where the patient organisation operates.

3

1 **Disclosure details**2 **Table 3. Reporting of payments to patient organizations by pharmaceutical companies:**  
3 **comparison of company websites and Disclosure UK HCOs database**

<b>Company</b>	<b>Company website only</b>	<b>HCOs database only</b>	<b>Both</b>
Abbvie	X		
Alexion	X		
Almirall	X		
Alnylam			X
Amgen			X
Amryt	X		
Astellas			X
AstraZeneca			X
BMS			X
Bayer			X
Bial		X	
BioMarin			X
Biogen	X		
BlueBird	X		
Boehringer Ingelheim			X
Britannia			X
CSL Behring	X		
Camurus			X
Celgene			X
Chiesi			X
Chugai	X		
Clinuvel	X		
Daiichi Sankyo			X
Diurnal	X		
Eisai			X
Eli Lilly			X
Ever			X
Ferring		X	
Flynn		X	
GSK			X
GW			X
Gilead		X	
Grünenthal			X
Guerbet		X	
HRA		X	
Immedica	X		
Indivior	X		
Intercept	X		
Ipsen		X	
Janssen			X

<b>LEO</b>	X		
<b>Lundbeck</b>			X
<b>Lupin</b>	X		
<b>MSD</b>			X
<b>Merck</b>			X
<b>Merz</b>			X
<b>Napp</b>			X
<b>Norgine</b>		X	
<b>Novartis</b>			X
<b>Novo Nordisk</b>			X
<b>Octapharma</b>		X	
<b>PTC</b>	X		
<b>Pfizer</b>			X
<b>Pharmasure</b>		X	
<b>Pierre Fabre</b>			X
<b>Recordati</b>	X		
<b>Roche</b>			X
<b>Rosemont</b>			X
<b>Sandoz</b>		X	
<b>Sanofi</b>			X
<b>Santen</b>	X		
<b>Seqirus</b>	X		
<b>Servier</b>	X		
<b>Shionogi</b>		X	
<b>Shire</b>			X
<b>Sobi</b>	X		
<b>Takeda</b>			X
<b>Teva</b>		X	
<b>Tillotts</b>	X		
<b>UCB</b>			X
<b>Valneva</b>	X		
<b>Veriton</b>		X	
<b>Vifor</b>			X
<b>Zogenix</b>	X		
<b>Total (n; %)</b>	24; 32%	14; 19%	36; 49%

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2 **Table 4. Reporting of payments to patient organizations by pharmaceutical companies:**  
3 **payments disclosed on company websites and Disclosure UK HCOs database**

<b>Company</b>	<b>Payments reported on company website (£)</b>	<b>Payments reported on HCOs database (£)</b>	<b>Total</b>
<b>Abbvie</b>	£ 371,503	£ -	£ 371,503
<b>Alexion</b>	£ 168,925	£ -	£ 168,925
<b>Almirall</b>	£ 9,775	£ -	£ 9,775
<b>Alnylam</b>	£ 51,559	£ 14,050	£ 65,609
<b>Amgen</b>	£ 347,757	£ 68,845	£ 416,602

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<b>Amryt</b>	£ 45,413	£ -	£ 45,413
<b>Astellas</b>	£ 94,583	£ 13,071	£ 107,654
<b>AstraZeneca</b>	£ 326,201	£ 88,175	£ 414,376
<b>BMS</b>	£ 517,082	£ 17,750	£ 534,832
<b>Bayer</b>	£ 171,758	£ 9,098	£ 180,856
<b>Bial</b>	£ -	£ 5,500	£ 5,500
<b>BioMarin</b>	£ 411,912	£ 310,455	£ 722,367
<b>Biogen</b>	£ 663,142	£ -	£ 663,142
<b>BlueBird</b>	£ 94,000	£ -	£ 94,000
<b>Boehringer Ingelheim</b>	£ 79,762	£ 30,000	£ 109,762
<b>Britannia</b>	£ 35,000	£ 2,030	£ 37,030
<b>CSL Behring</b>	£ 152,192	£ -	£ 152,192
<b>Camurus</b>	£ 13,168	£ 6,500	£ 19,668
<b>Celgene</b>	£ 310,329	£ 640	£ 310,969
<b>Chiesi</b>	£ 602,259	£ 60,000	£ 662,259
<b>Chugai</b>	£ 62,092	£ -	£ 62,092
<b>Clinuvel</b>	£ 1,000	£ -	£ 1,000
<b>Daiichi Sankyo</b>	£ 57,879	£ 329,385	£ 387,264
<b>Diurnal</b>	£ 6,000	£ -	£ 6,000
<b>Eisai</b>	£ 476,271	£ 183,207	£ 659,478
<b>Eli Lilly</b>	£ 874,288	£ 62,690	£ 936,978
<b>Ever</b>	£ 18,934	£ 18,934	£ 37,867
<b>Ferring</b>	£ -	£ 38,000	£ 38,000
<b>Flynn</b>	£ -	£ 8,002	£ 8,002
<b>GSK</b>	£ 325,410	£ 159,064	£ 484,474
<b>GW</b>	£ 98,788	£ 303	£ 99,091
<b>Gilead</b>	£ -	£ 417,448	£ 417,448
<b>Grünenthal</b>	£ 4,200	£ 1,000	£ 5,200
<b>Guerbet</b>	£ -	£ 17,000	£ 17,000
<b>HRA</b>	£ -	£ 10,000	£ 10,000
<b>Immedica</b>	£ 19,954	£ -	£ 19,954
<b>Indivior</b>	£ 1,200	£ -	£ 1,200
<b>Intercept</b>	£ 71,712	£ -	£ 71,712
<b>Ipsen</b>	£ -	£ 50,050	£ 50,050
<b>Janssen</b>	£ 1,170,768	£ 10,000	£ 1,180,768
<b>LEO</b>	£ 78,633	£ -	£ 78,633
<b>Lundbeck</b>	£ 89,400	£ 40,309	£ 129,709
<b>Lupin</b>	£ 24,000	£ -	£ 24,000
<b>MSD</b>	£ 537,632	£ 225,287	£ 762,919
<b>Merck</b>	£ 763,885	£ 1,000	£ 764,885
<b>Merz</b>	£ 31,114	£ 5,789	£ 36,903
<b>Napp</b>	£ 8,000	£ 18,020	£ 26,020
<b>Norgine</b>	£ -	£ 1,240	£ 1,240
<b>Novartis</b>	£ 1,442,037	£ 46,812	£ 1,488,849
<b>Novo Nordisk</b>	£ 452,113	£ 1,411,598	£ 1,863,711

<b>Octapharma</b>	£ -	£ 2,995	£ 2,995
<b>PTC</b>	£ 151,433	£ -	£ 151,433
<b>Pfizer</b>	£ 1,360,510	£ 509,793	£ 1,870,303
<b>Pharmasure</b>	£ -	£ 6,000	£ 6,000
<b>Pierre Fabre</b>	£ 50,010	£ 34,096	£ 84,106
<b>Recordati</b>	£ 14,500	£ -	£ 14,500
<b>Roche</b>	£ 1,169,578	£ 101,395	£ 1,270,973
<b>Rosemont</b>	£ 200	£ 200	£ 400
<b>Sandoz</b>	£ -	£ 20,000	£ 20,000
<b>Sanofi</b>	£ 1,262,802	£ 3,825	£ 1,266,627
<b>Santen</b>	£ 38,170	£ -	£ 38,170
<b>Seqirus</b>	£ 105,000	£ -	£ 105,000
<b>Servier</b>	£ 17,163	£ -	£ 17,163
<b>Shionogi</b>	£ -	£ 17,000	£ 17,000
<b>Shire</b>	£ 555,244	£ 53,980	£ 609,224
<b>Sobi</b>	£ 132,988	£ -	£ 132,988
<b>Takeda</b>	£ 420,549	£ 17,270	£ 437,819
<b>Teva</b>	£ -	£ 51,410	£ 51,410
<b>Tillotts</b>	£ 830	£ -	£ 830
<b>UCB</b>	£ 1,493,896	£ 35,378	£ 1,529,274
<b>Valneva</b>	£ 59,512	£ -	£ 59,512
<b>Veriton</b>	£ -	£ 15,000	£ 15,000
<b>Vifor</b>	£ 58,083	£ 12,000	£ 70,083
<b>Zogenix</b>	£ 43,625	£ -	£ 43,625
<b>Total (£; %)</b>	£18,015,722; 80%	£4,561,593; 20%	£22,577,314; 100%

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Table 5. Companies' commercial interests by ICD-11 codes according to 2020 payments

Company	ICD-11																		
	01	02	03	04	05	06	08	09	11	12	13	14	15	16	18	19	20	22	Other
Abbvie	1	1	0	0	0	0	1	0	0	0	1	1	1	0	0	0	0	0	0
Alexion	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Almirall	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0
Alnylam	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Amgen	0	1	1	0	0	0	0	0	0	0	1	1	1	0	0	0	0	0	0
Amryt	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Astellas	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
AstraZeneca	0	1	0	0	1	0	0	0	1	0	0	0	0	1	0	0	0	0	0
BMS	0	1	0	0	0	0	1	0	1	0	0	0	1	0	0	0	0	0	0
Bayer	0	1	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0
Bial	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
BioMarin	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Biogen	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	0	0	0	0
BlueBird	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
Boehringer Ingelheim	0	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0
Britannia	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
CSL Behring	1	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Camurus	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Celgene	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Chiesi	0	0	1	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0
Chugai	0	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0
Clinuvel	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Daiichi Sankyo	0	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0
Diurnal	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0

Eisai	0	1	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0
Eli Lilly	0	1	0	0	1	0	1	0	0	0	0	1	1	0	0	0	0	0	0
Ever	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
Ferring	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0
Flynn	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0
GSK	1	1	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0
GW	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Gilead	1	1	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
Grünenthal	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Guerbet	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0
HRA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Immedica	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Indivior	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Intercept	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
Ipsen	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
Janssen	1	1	0	0	0	0	0	0	1	0	1	1	0	0	0	0	0	0	0
LEO	0	0	0	0	0	0	0	0	1	0	0	1	0	0	0	0	0	0	0
Lundbeck	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0
Lupin	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
MSD	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Merck	0	1	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	0
Merz	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Napp	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Norgine	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Novartis	0	1	1	0	0	0	1	1	1	0	0	1	1	0	0	0	0	0	0
Novo Nordisk	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	0
Octapharma	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
PTC	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
Pfizer	1	1	1	0	1	0	1	0	1	0	1	0	1	0	0	0	1	0	0
Pharmasure	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0

<b>Pierre Fabre</b>	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0
<b>Recordati</b>	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Roche</b>	0	1	0	0	0	0	1	0	0	1	1	0	0	0	1	0	0	0	0
<b>Rosemont</b>	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Sandoz</b>	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Sanofi</b>	1	1	1	1	1	0	1	0	1	0	0	1	1	1	0	0	0	0	0
<b>Santen</b>	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0
<b>Seqirus</b>	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Servier</b>	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Shionogi</b>	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Shire</b>	0	0	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Sobi</b>	0	1	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Takeda</b>	0	1	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0
<b>Teva</b>	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Tillotts</b>	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
<b>UCB</b>	0	0	1	0	0	0	1	0	0	0	0	1	1	0	0	0	0	0	0
<b>Valneva</b>	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Veriton</b>	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Vifor</b>	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>Zogenix</b>	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0

Notes: This table reflects whether companies had a definite or probable interest in the ICD-11 code based on their pipeline or portfolio (1 = yes, 0 = no). Please note that companies' interests were opportunistically screened only in disease areas where they made a payment to a specific patient organisation, and therefore this table should not be considered exhaustive. The table refers payments made in 2020 only.

Legend: 01 Certain infectious or parasitic diseases; 02 Neoplasms; 03 Diseases of the blood or blood-forming organs; 04 Diseases of the immune system; 05 Endocrine, nutritional or metabolic diseases; 06 Mental, behavioural or neurodevelopmental disorders; 08 Diseases of the nervous system; 09 Diseases of the visual system; 11 Diseases of the circulatory system; 12 Diseases of the respiratory system; 13 Diseases of the digestive system; 14 Diseases of the skin; 15 Diseases of the musculoskeletal system or connective tissue; 16 Diseases of the genitourinary system; 18 Pregnancy, childbirth or the puerperium; 19 Certain conditions originating in the perinatal period; 20 Developmental anomalies; 22 Injury, poisoning or certain other consequences of external causes; Other. Other indicates disease areas where patient organisations operate that could not be classified as any ICD-11 codes.



**Table 6. List of patient organisations receiving payments in 2020**

Standardised name	Charity number	Link
Acacia Mews Care Home	1174346	<a href="https://www.nhs.uk/services/Careproviders/Overview/DefaultView.aspx?id=47011">https://www.nhs.uk/services/Careproviders/Overview/DefaultView.aspx?id=47011</a>
Action Bladder Cancer UK	1164374	<a href="https://actionbladdercanceruk.org/">https://actionbladdercanceruk.org/</a>
Action for Pulmonary Fibrosis	1152399	<a href="https://www.actionpf.org/">https://www.actionpf.org/</a>
Action On Pre-Eclampsia	1013557	<a href="https://action-on-pre-eclampsia.org.uk/">https://action-on-pre-eclampsia.org.uk/</a>
Action on Smoking and Health - Wales	1120834	<a href="https://ash.wales/">https://ash.wales/</a>
Action Duchenne	1101971	<a href="https://www.actionduchenne.org/">https://www.actionduchenne.org/</a>
Adfam	1067428	<a href="https://adfam.org.uk/">https://adfam.org.uk/</a>
Africa Advocacy Foundation	1164778	<a href="https://www.africadvocacy.org/">https://www.africadvocacy.org/</a>
African-Caribbean Leukaemia Trust	1119516	<a href="https://aact.org/">https://aact.org/</a>
Age UK	1128267	<a href="https://www.ageuk.org.uk/">https://www.ageuk.org.uk/</a>
Alex - The Leukodystrophy Charity	1106008	<a href="https://www.alextlc.org/">https://www.alextlc.org/</a>
ALK Positive Lung Cancer	1181171	<a href="https://www.alkpositive.org.uk/">https://www.alkpositive.org.uk/</a>
Alkaptonuria Society	1101052	<a href="https://akusociety.org/">https://akusociety.org/</a>
Allergy UK	1094231	<a href="https://www.allergyuk.org/">https://www.allergyuk.org/</a>
Alliance for Heart Failure	N/A	<a href="https://allianceforheartfailure.org/">https://allianceforheartfailure.org/</a>
Alzheimer Scotland	SC022315	<a href="https://www.alzscot.org/">https://www.alzscot.org/</a>
Alzheimer's Support	1048314	<a href="https://www.alzheimerswiltshire.org.uk/">https://www.alzheimerswiltshire.org.uk/</a>
Alzheimer's Research UK	1077089	<a href="https://www.alzheimersresearchuk.org/">https://www.alzheimersresearchuk.org/</a>
Alzheimer's Society	296645	<a href="https://www.alzheimers.org.uk/">https://www.alzheimers.org.uk/</a>
Amyloidosis Patients Association	1183624	<a href="https://register-of-charities.charitycommission.gov.uk/charity-details/?regid=1183624&amp;subid=0">https://register-of-charities.charitycommission.gov.uk/charity-details/?regid=1183624&amp;subid=0</a>
Anthony Nolan	803716	<a href="https://www.anthonynolan.org/">https://www.anthonynolan.org/</a>
Anticoagulation UK	1090250	<a href="https://register-of-charities.charitycommission.gov.uk/charity-details/?regid=1090250&amp;subid=0">https://register-of-charities.charitycommission.gov.uk/charity-details/?regid=1090250&amp;subid=0</a>
AOFAC Foundation	1162155	<a href="https://aofacfoundation.org/">https://aofacfoundation.org/</a>
Aplastic Anaemia Trust	1107539	<a href="https://www.theaat.org.uk/">https://www.theaat.org.uk/</a>
APS Support UK	1138116	<a href="https://aps-support.org.uk/">https://aps-support.org.uk/</a>
Arthritis and Musculoskeletal Alliance	1108851	<a href="http://arma.uk.net/">http://arma.uk.net/</a>
Aspens	1171446	<a href="https://www.aspens.org.uk/">https://www.aspens.org.uk/</a>
Association for Glycogen Storage Disease	1132271	<a href="https://agsd.org.uk/">https://agsd.org.uk/</a>
Asthma + Lung UK	326730	<a href="https://www.asthma.org.uk/">https://www.asthma.org.uk/</a>
Astriid	1176645	<a href="https://astriid.org/">https://astriid.org/</a>
Atrial Fibrillation Association	1122442	Supporting children terminally ill
Axial Spondylitis International Federation	1173902	<a href="https://asif.info/">https://asif.info/</a>
Baby Lifeline	1006457	<a href="https://www.babylifeline.org.uk/">https://www.babylifeline.org.uk/</a>
Bath Institute for Rheumatic Diseases	1040650	<a href="https://www.birdbath.org.uk/">https://www.birdbath.org.uk/</a>

Batten Disease Family Association	1084908	<a href="http://www.bdfa-uk.org.uk/">http://www.bdfa-uk.org.uk/</a>
Bipolar UK	293340	<a href="https://www.bipolaruk.org/">https://www.bipolaruk.org/</a>
Bladder Health UK	1149973	<a href="https://bladderhealthuk.org/">https://bladderhealthuk.org/</a>
Bliss	1002973	<a href="https://www.bliss.org.uk/">https://www.bliss.org.uk/</a>
Blood Cancer Alliance	N/A	<a href="https://www.bloodcanceralliance.org/">https://www.bloodcanceralliance.org/</a>
Blood Cancer UK	216032	<a href="https://bloodcancer.org.uk/">https://bloodcancer.org.uk/</a>
BME Cancer Communities	1182806	<a href="https://www.bmecancer.com/">https://www.bmecancer.com/</a>
Bowel Cancer UK	1071038	<a href="https://www.bowelcanceruk.org.uk/">https://www.bowelcanceruk.org.uk/</a>
Brains Trust	1114634	<a href="https://brainstrust.org.uk/">https://brainstrust.org.uk/</a>
Breast Cancer Haven (The Haven)	3291851	<a href="https://www.breastcancerhaven.org.uk/">https://www.breastcancerhaven.org.uk/</a>
Breast Cancer Now	1160558	<a href="https://breastcancer.org.uk/">https://breastcancer.org.uk/</a>
British Association of the Study of the Liver	1106320	<a href="https://www.basl.org.uk/">https://www.basl.org.uk/</a>
British Heart Foundation	225971	<a href="https://www.bhf.org.uk/">https://www.bhf.org.uk/</a>
British Inherited Metabolic Disease Group	1184024	<a href="https://www.bimdg.org.uk/site/index.asp">https://www.bimdg.org.uk/site/index.asp</a>
British Liver Trust	298858	<a href="https://britishlivertrust.org.uk/">https://britishlivertrust.org.uk/</a>
British Paediatric Neurology Association	1159115	<a href="https://bpna.org.uk/">https://bpna.org.uk/</a>
British Porphyria Association	1089609	<a href="http://porphyria.org.uk/">http://porphyria.org.uk/</a>
British Skin Foundation	1171373	<a href="https://www.britishskinfoundation.org.uk/">https://www.britishskinfoundation.org.uk/</a>
British Society for Heart Failure	1075720	<a href="https://www.bsh.org.uk/">https://www.bsh.org.uk/</a>
British Society of Echocardiography	1093808	<a href="https://www.bsecho.org/">https://www.bsecho.org/</a>
British Thyroid Foundation	1006391	<a href="https://www.btf-thyroid.org/">https://www.btf-thyroid.org/</a>
Cambridge Rare Disease Network	1166365	<a href="https://www.camraredisease.org/">https://www.camraredisease.org/</a>
Cancer 52	7994413	<a href="https://www.cancer52.org.uk/">https://www.cancer52.org.uk/</a>
Cancer Black Care	1086465	<a href="https://www.cancerblackcare.org.uk/">https://www.cancerblackcare.org.uk/</a>
Cancer Focus Northern Ireland	101307	<a href="https://cancerfocusni.org/">https://cancerfocusni.org/</a>
Cancer Research UK	1089464	<a href="https://www.cancerresearchuk.org/">https://www.cancerresearchuk.org/</a>
Cancer Support Scotland	SC012867	<a href="https://www.cancersupportscotland.org/">https://www.cancersupportscotland.org/</a>
Cancer Support UK	1105703	<a href="https://cancersupportuk.org/">https://cancersupportuk.org/</a>
CancerCare	1120048	<a href="https://cancercare.org.uk/">https://cancercare.org.uk/</a>
Cara Trust	328124	<a href="https://www.madtrust.org.uk/project/the-cara-trust/">https://www.madtrust.org.uk/project/the-cara-trust/</a>
Cardiomyopathy UK	1164263	<a href="https://www.cardiomyopathy.org/">https://www.cardiomyopathy.org/</a>
Carers UK	N/A	<a href="https://www.carersuk.org/">https://www.carersuk.org/</a>
Changing Faces	1011222	<a href="https://www.changingfaces.org.uk/">https://www.changingfaces.org.uk/</a>
Child Growth Foundation	1172807	<a href="https://childgrowthfoundation.org/">https://childgrowthfoundation.org/</a>
Childhood Trust	1154032	<a href="https://www.childhoodtrust.org.uk/">https://www.childhoodtrust.org.uk/</a>
Children's Cancer and Leukaemia Group	1182637	<a href="https://www.cclg.org.uk/">https://www.cclg.org.uk/</a>
Children's HIV Association	1122356	<a href="https://www.chiva.org.uk/">https://www.chiva.org.uk/</a>
Children's Trust	288018	<a href="https://www.thechildrenstrust.org.uk/">https://www.thechildrenstrust.org.uk/</a>
Children's Burns Trust	1082084	<a href="https://www.cbtrust.org.uk/">https://www.cbtrust.org.uk/</a>

Cholangiocarcinoma Charity	1091915	<a href="https://ammf.org.uk/">https://ammf.org.uk/</a>
Chronic Lymphocytic Leukaemia Support Association	1178482	<a href="https://www.clisupport.org.uk/">https://www.clisupport.org.uk/</a>
Coalition for Life-Course Immunisation	1182662	<a href="https://www.cl-ci.org/">https://www.cl-ci.org/</a>
Confederation of Meningitis Organisations	1091105	<a href="https://www.comomeningitis.org/">https://www.comomeningitis.org/</a>
Contact a Family	284912	<a href="https://contact.org.uk/">https://contact.org.uk/</a>
Crohn's and Colitis UK	1117148	<a href="https://www.crohnsandcolitis.org.uk/">https://www.crohnsandcolitis.org.uk/</a>
Cystic Fibrosis Trust	1079049	<a href="https://www.cysticfibrosis.org.uk/">https://www.cysticfibrosis.org.uk/</a>
Dementia UK	1039404	<a href="https://www.dementiauk.org/">https://www.dementiauk.org/</a>
Dementia Club UK	1168397	<a href="https://dementiclubuk.org.uk/">https://dementiclubuk.org.uk/</a>
Diabetes UK	215199	<a href="https://www.diabetes.org.uk/">https://www.diabetes.org.uk/</a>
Diana Award	1117288	<a href="https://diana-award.org.uk/">https://diana-award.org.uk/</a>
DMD Pathfinders	1155884	<a href="https://www.pathfindersalliance.org.uk/">https://www.pathfindersalliance.org.uk/</a>
Down Syndrome International	1091843	<a href="https://www.ds-int.org/">https://www.ds-int.org/</a>
Downs Syndrome Association	1061474	<a href="https://www.downs-syndrome.org.uk/">https://www.downs-syndrome.org.uk/</a>
Dravet Syndrome UK	1128289	<a href="https://www.dravet.org.uk/">https://www.dravet.org.uk/</a>
DrugFAM	1123316	<a href="https://www.drugfam.co.uk/#">https://www.drugfam.co.uk/#</a>
Duchenne UK	1147094	<a href="https://www.duchenneuk.org/">https://www.duchenneuk.org/</a>
Dystonia UK	1062595	<a href="https://www.dystonia.org.uk/">https://www.dystonia.org.uk/</a>
East North Hertfordshire NHS Trust	1053338	<a href="https://www.enherts-tr.nhs.uk/">https://www.enherts-tr.nhs.uk/</a>
East Sussex Healthcare NHS Trust	1058599	<a href="https://www.esht.nhs.uk/">https://www.esht.nhs.uk/</a>
Ecancer	1176307	<a href="https://ecancer.org/en/">https://ecancer.org/en/</a>
Eczema Outreach Support	SC042392	<a href="https://www.eos.org.uk/">https://www.eos.org.uk/</a>
Encephalitis Society	1087843	<a href="https://www.encephalitis.info/">https://www.encephalitis.info/</a>
Epilepsy Action	234343	<a href="https://www.epilepsy.org.uk/?gclid=CjwKCAiAsNKQBhAPEiwAB-15zXsMWEMg1x_J-blYzK3HQGZujp-zoejjkEA_sYpKqYxct5LuE_sV6hoC1t8QAvD_BwE">https://www.epilepsy.org.uk/?gclid=CjwKCAiAsNKQBhAPEiwAB-15zXsMWEMg1x_J-blYzK3HQGZujp-zoejjkEA_sYpKqYxct5LuE_sV6hoC1t8QAvD_BwE</a>
Epilepsy Consortium Scotland	N/A	<a href="http://www.epilepsyconsortiumscotland.co.uk/">http://www.epilepsyconsortiumscotland.co.uk/</a>
Epilepsy Research UK	1100394	<a href="https://epilepsyresearch.org.uk/">https://epilepsyresearch.org.uk/</a>
Epilepsy Scotland	SC000067	<a href="https://www.epilepyscotland.org.uk/">https://www.epilepyscotland.org.uk/</a>
Epilepsy Society	206186	<a href="https://epilepysociety.org.uk/">https://epilepysociety.org.uk/</a>
Errol Mckellar Foundation	1181574	<a href="https://www.theerrolmckellarfoundation.com/">https://www.theerrolmckellarfoundation.com/</a>
European Parkinson's Disease Association	1163211	<a href="https://www.epda.eu.com/">https://www.epda.eu.com/</a>
Eve Appeal	1091708	<a href="https://eveappeal.org.uk/">https://eveappeal.org.uk/</a>
Familial Hypercholesterolaemia Network	1170731	<a href="https://fheurope.org/">https://fheurope.org/</a>
FareShare	1100051	<a href="https://fareshare.org.uk/">https://fareshare.org.uk/</a>
Favor UK	N/A	<a href="https://www.facesandvoicesofrecoveryuk.org/">https://www.facesandvoicesofrecoveryuk.org/</a>

Fertility Network UK	1099960	<a href="https://fertilitynetworkuk.org/">https://fertilitynetworkuk.org/</a>
Fight Bladder Cancer	1157763	<a href="https://www.fightbladdercancer.co.uk/">https://www.fightbladdercancer.co.uk/</a>
Fight for Sight UK	1111438	<a href="https://www.fightforsight.org.uk/">https://www.fightforsight.org.uk/</a>
Findacure	1149646	<a href="https://www.rarebeacon.org/about-us/our-journey/">https://www.rarebeacon.org/about-us/our-journey/</a>
Gauchers Association	1095657	<a href="https://www.gaucher.org.uk/">https://www.gaucher.org.uk/</a>
Gene People	1141583	<a href="https://genepeople.org.uk/">https://genepeople.org.uk/</a>
Genetic Alliance UK	1114195	<a href="https://geneticalliance.org.uk/">https://geneticalliance.org.uk/</a>
GetYourBellyOut	11276246	<a href="https://getyourbellyout.org.uk/">https://getyourbellyout.org.uk/</a>
GIST Cancer UK	1129219	<a href="https://www.gistcancer.org.uk/">https://www.gistcancer.org.uk/</a>
Global Action on Men's Health	1183428	<a href="https://gamh.org/">https://gamh.org/</a>
GO Girls	1179108	<a href="https://www.gogirlssupport.org/">https://www.gogirlssupport.org/</a>
Gorlin Syndrome Group	1197282	<a href="https://gorlingroup.org/">https://gorlingroup.org/</a>
Guts UK	1137029	<a href="https://gutscharity.org.uk/">https://gutscharity.org.uk/</a>
Haemochromatosis UK	1001307	<a href="https://www.haemochromatosis.org.uk/">https://www.haemochromatosis.org.uk/</a>
Haemophilia Scotland	SC044298	<a href="https://haemophilia.scot/">https://haemophilia.scot/</a>
Haemophilia Society	288260	<a href="https://haemophilia.org.uk/">https://haemophilia.org.uk/</a>
Headway East London	1083910	<a href="https://headwayeastlondon.org/">https://headwayeastlondon.org/</a>
Heart UK	1003904	<a href="https://www.heartuk.org.uk/">https://www.heartuk.org.uk/</a>
Heartburn Cancer UK	1136413	<a href="https://www.heartburncanceruk.org/">https://www.heartburncanceruk.org/</a>
Helen & Douglas House	1085951	<a href="https://www.helenanddouglas.org.uk/">https://www.helenanddouglas.org.uk/</a>
Hepatitis C Coalition	N/A	<a href="http://www.hepc-coalition.uk/">http://www.hepc-coalition.uk/</a>
Hepatitis C Trust	1104279	<a href="http://hepctrust.org.uk/">http://hepctrust.org.uk/</a>
Hereditary Angioedema UK	1152591	<a href="https://www.haeuk.org/">https://www.haeuk.org/</a>
Hidradenitis Suppurativa Trust	1177819	<a href="https://painuk.org/members/charities/hidradenitis-suppurativa-trust/">https://painuk.org/members/charities/hidradenitis-suppurativa-trust/</a>
Histiocytosis UK	1158789	<a href="https://www.histiouk.org/">https://www.histiouk.org/</a>
HIV i-Base	1081905	<a href="https://i-base.info/">https://i-base.info/</a>
HIV Scotland	SC033951	<a href="https://www.hiv.scot/">https://www.hiv.scot/</a>
Human Story Theatre	1173504	<a href="https://humanstorytheatre.com/about-us/">https://humanstorytheatre.com/about-us/</a>
Huntington's Disease Association	296453	<a href="https://www.hda.org.uk/">https://www.hda.org.uk/</a>
Huntington's Disease Youth Organization	1145781	<a href="https://en.hdyo.org/">https://en.hdyo.org/</a>
Immune Deficiency Patient Group of Wales	N/A	<a href="https://www.facebook.com/tommy.browne.idpgw/">https://www.facebook.com/tommy.browne.idpgw/</a>
Immune Thrombocytopenia Support Association	1064480	<a href="https://www.itpsupport.org.uk/index.php/en/">https://www.itpsupport.org.uk/index.php/en/</a>
Independent Cancer Patients' Voice	1138456	<a href="http://www.independentcancerpatientsvoice.org.uk/">http://www.independentcancerpatientsvoice.org.uk/</a>
Intensive Care Society	1039236	<a href="https://www.ics.ac.uk/">https://www.ics.ac.uk/</a>
International Alliance of Patients' Organizations	1155577	<a href="https://www.iapo.org.uk/">https://www.iapo.org.uk/</a>
International Brain Tumour Alliance	N/A	<a href="https://theibta.org/">https://theibta.org/</a>
International Gaucher Alliance	6653373	<a href="https://gaucheralliance.org/home">https://gaucheralliance.org/home</a>
International Headache Society	1042574	<a href="https://ihs-headache.org/en/">https://ihs-headache.org/en/</a>
International Longevity Centre UK	1080496	<a href="https://ilcuk.org.uk/">https://ilcuk.org.uk/</a>

International Niemann-Pick Disease Alliance	1150256	<a href="https://www.inpda.org/">https://www.inpda.org/</a>
International Patient Organisation for Primary Immunodeficiencies	1058005	<a href="https://ipopi.org/">https://ipopi.org/</a>
Invisible Cafe	N/A	<a href="https://theinvisiblecafe.co.uk/">https://theinvisiblecafe.co.uk/</a>
Isabel Hospice Limited	1046826	<a href="https://www.isabelhospice.org.uk/">https://www.isabelhospice.org.uk/</a>
Jo's Cervical Cancer Trust	1133542	<a href="https://www.jostrust.org.uk/">https://www.jostrust.org.uk/</a>
Juvenile Diabetes Research Foundation	295716	<a href="https://jdrf.org.uk/">https://jdrf.org.uk/</a>
Karen Clifford Skcin cancer charity	1150048	<a href="https://www.skcin.org/">https://www.skcin.org/</a>
Kent Autistic Trust	801965	<a href="https://www.kentautistictrust.org/">https://www.kentautistictrust.org/</a>
Kent MS Therapy Centre	801382	<a href="https://kentmstc.org.uk/">https://kentmstc.org.uk/</a>
Kidney Cancer Support Network	1164238	<a href="https://actionkidneycancer.org/">https://actionkidneycancer.org/</a>
Kidney Cancer UK	1120146	<a href="https://www.kcuk.org.uk/">https://www.kcuk.org.uk/</a>
Kidney Care UK	270288	<a href="https://www.kidneycareuk.org/">https://www.kidneycareuk.org/</a>
Kidney Research UK	252892	<a href="https://www.kidneyresearchuk.org/">https://www.kidneyresearchuk.org/</a>
Leukaemia CARE	1183890	<a href="https://www.leukaemiacare.org.uk/">https://www.leukaemiacare.org.uk/</a>
Leukaemia UK	1154856	<a href="https://www.leukaemiauk.org.uk/">https://www.leukaemiauk.org.uk/</a>
Liver4Life	1152618	<a href="https://www.liver4life.org.uk/">https://www.liver4life.org.uk/</a>
Lupus UK	1051610	<a href="https://www.lupusuk.org.uk/">https://www.lupusuk.org.uk/</a>
Lymphoma Action	1068395	<a href="https://lymphoma-action.org.uk/about-us">https://lymphoma-action.org.uk/about-us</a>
Macmillan Cancer Support	261017	<a href="https://www.macmillan.org.uk/">https://www.macmillan.org.uk/</a>
Macular Society	2177039	<a href="https://www.macularsociety.org/">https://www.macularsociety.org/</a>
Maggie's Centres	SC024414	<a href="https://www.maggies.org/">https://www.maggies.org/</a>
Maypole Project	1120163	<a href="https://www.themaypoleproject.co.uk/">https://www.themaypoleproject.co.uk/</a>
MDS UK Support Group	1145214	<a href="https://mdspatientsupport.org.uk/">https://mdspatientsupport.org.uk/</a>
Meath Epilepsy Charity	200359	<a href="https://www.meath.org.uk/">https://www.meath.org.uk/</a>
Medics 4 Rare Diseases	1183996	<a href="https://www.m4rd.org/history/">https://www.m4rd.org/history/</a>
Melanoma Focus	1124716	<a href="https://melanomafocus.org/">https://melanomafocus.org/</a>
Melanoma Fund	1085969	<a href="https://www.melanoma-fund.co.uk/">https://www.melanoma-fund.co.uk/</a>
Melanoma UK	1157635	<a href="https://www.melanomauk.org.uk/">https://www.melanomauk.org.uk/</a>
Memorylane Eastbourne	1163541	<a href="https://www.memorylaneeastbourne.co.uk/">https://www.memorylaneeastbourne.co.uk/</a>
Meningitis Now	803016	<a href="https://www.meningitisnow.org/">https://www.meningitisnow.org/</a>
Meningitis Research Foundation	1091105	<a href="https://www.meningitis.org/">https://www.meningitis.org/</a>
Menopause Support	N/A	<a href="https://menopausesupport.co.uk/">https://menopausesupport.co.uk/</a>
Mental Health UK	1170815	<a href="https://mentalhealth-uk.org/">https://mentalhealth-uk.org/</a>
Mersey Region Epilepsy Association	504366	<a href="https://www.epilepsymersey.org.uk/">https://www.epilepsymersey.org.uk/</a>
Mesothelioma UK	1177039	<a href="https://www.mesothelioma.uk.com/">https://www.mesothelioma.uk.com/</a>
Metabolic Support UK	1089588	<a href="https://www.metabolicsupportuk.org/">https://www.metabolicsupportuk.org/</a>
Migraine Trust	1081300	<a href="https://migrainetrust.org/">https://migrainetrust.org/</a>
Motor Neurone Disease Association	294354	<a href="https://www.mndassociation.org/">https://www.mndassociation.org/</a>
Mouth Cancer Foundation	1109298	<a href="https://www.mouthcancerfoundation.org/">https://www.mouthcancerfoundation.org/</a>
MPN Voice	1160316	<a href="https://www.mpnvoice.org.uk/">https://www.mpnvoice.org.uk/</a>

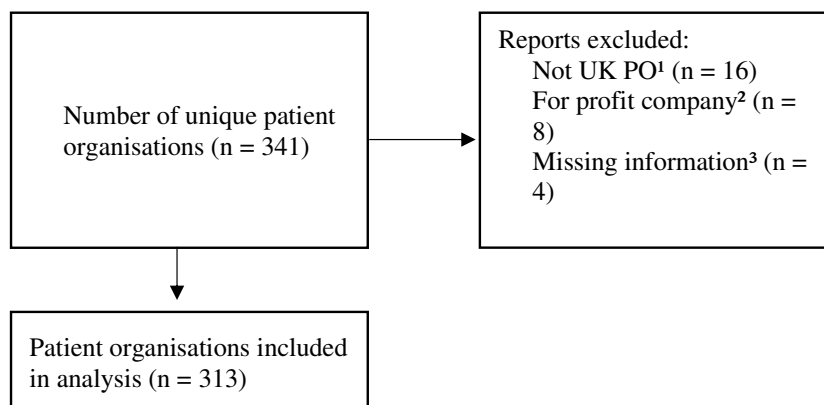
Multiple Sclerosis International Federation	1105321	<a href="https://www.msif.org/">https://www.msif.org/</a>
Multiple Sclerosis Society UK	1139257	<a href="https://www.mssociety.org.uk/">https://www.mssociety.org.uk/</a>
Multiple Sclerosis Therapy Centres	1031690	<a href="https://www.msntc.org.uk/">https://www.msntc.org.uk/</a>
Multiple Sclerosis Trust	1088353	<a href="https://mstrust.org.uk/">https://mstrust.org.uk/</a>
Muscular Dystrophy UK	205395	<a href="https://www.muscular dystrophyuk.org/">https://www.muscular dystrophyuk.org/</a>
My Name's Doddie Foundation	SC047871	<a href="https://www.mynamesdoddie.co.uk/">https://www.mynamesdoddie.co.uk/</a>
Myeloma UK	SC026116	<a href="https://www.myeloma.org.uk/">https://www.myeloma.org.uk/</a>
National AIDS Map	1011220	<a href="https://www.aidsmap.com/">https://www.aidsmap.com/</a>
National AIDS Trust	297977	<a href="https://www.nat.org.uk/">https://www.nat.org.uk/</a>
National Attention Deficit Disorder Information and Support Service	N/A	<a href="https://www.nhs.uk/services/service-directory/the-national-attention-deficit-disorder-information-and-support-service-address/N10498901">https://www.nhs.uk/services/service-directory/the-national-attention-deficit-disorder-information-and-support-service-address/N10498901</a>
National Axial Spondyloarthritis Society	1183175	<a href="https://nass.co.uk/">https://nass.co.uk/</a>
National Cancer Research Institute	1160609	<a href="https://www.ncri.org.uk/">https://www.ncri.org.uk/</a>
National Eczema Society	1009671	<a href="https://eczema.org/">https://eczema.org/</a>
National Federation of Prostate Cancer Support Groups	1163152	<a href="https://tackleprostate.org/">https://tackleprostate.org/</a>
National Kidney Federation	1106735	<a href="https://www.kidney.org.uk/">https://www.kidney.org.uk/</a>
National Rheumatoid Arthritis Society	1134859	<a href="https://nras.org.uk/">https://nras.org.uk/</a>
National Voices	1057711	<a href="https://www.nationalvoices.org.uk/">https://www.nationalvoices.org.uk/</a>
NAZ	1014056	<a href="https://www.naz.org.uk/">https://www.naz.org.uk/</a>
Neuroendocrine Cancer UK	1092386	<a href="https://www.neuroendocrinecancer.org.uk/">https://www.neuroendocrinecancer.org.uk/</a>
Neurological Alliance	1039034	<a href="https://www.neural.org.uk/">https://www.neural.org.uk/</a>
New Life Counselling	NI005568	<a href="https://www.amh.org.uk/">https://www.amh.org.uk/</a>
NHS Charities Together	1186569	<a href="https://nhscharitiestogether.co.uk/">https://nhscharitiestogether.co.uk/</a>
Nicole & Jessica Rich Foundation	N/A	<a href="https://thenicolerichfoundation.org.uk/">https://thenicolerichfoundation.org.uk/</a>
Niemann-Pick UK	1144406	<a href="https://www.npuk.org/">https://www.npuk.org/</a>
North Bristol NHS Trust	1055900	<a href="https://www.nbt.nhs.uk/">https://www.nbt.nhs.uk/</a>
Oral Health Foundation	263198	<a href="https://www.dentalhealth.org/">https://www.dentalhealth.org/</a>
Orchid	1080540	<a href="https://orchid-cancer.org.uk/">https://orchid-cancer.org.uk/</a>
Osteoporosis Dorset	1023507	<a href="https://www.osteodorset.org.uk/">https://www.osteodorset.org.uk/</a>
Ovacome	1159682	<a href="https://www.ovacome.org.uk/">https://www.ovacome.org.uk/</a>
Ovarian Cancer Action	1109743	<a href="https://ovarian.org.uk/">https://ovarian.org.uk/</a>
Over the Wall	1075361	<a href="https://www.otw.org.uk/">https://www.otw.org.uk/</a>
Pain Concern	SC023559	<a href="https://painconcern.org.uk/">https://painconcern.org.uk/</a>
Pancreatic Cancer Action	1137689	<a href="https://pancreaticcanceraction.org/">https://pancreaticcanceraction.org/</a>
Pancreatic Cancer UK	1112708	<a href="https://www.pancreaticcancer.org.uk/">https://www.pancreaticcancer.org.uk/</a>
Parathyroid UK	N/A	<a href="https://parathyroiduk.org/">https://parathyroiduk.org/</a>
Parkinson's UK	258197	<a href="https://www.parkinsons.org.uk/">https://www.parkinsons.org.uk/</a>
Patient Information Forum	N/A	<a href="https://pifonline.org.uk/">https://pifonline.org.uk/</a>
Patients Association	1006733	<a href="https://www.patients-association.org.uk/">https://www.patients-association.org.uk/</a>

Patients On Intravenous and Nasogastric Nutrition Therapy	1157655	<a href="https://pinnt.com/Home.aspx">https://pinnt.com/Home.aspx</a>
Paula Carr Diabetes Trust	801596	<a href="https://www.paulacarrdiabetestrust.co.uk/">https://www.paulacarrdiabetestrust.co.uk/</a>
PBC Foundation UK	SC025619	<a href="https://www.pbcfoundation.org.uk/">https://www.pbcfoundation.org.uk/</a>
Pilgrims Hospice	293968	<a href="https://www.pilgrimshospices.org/">https://www.pilgrimshospices.org/</a>
Pituitary Foundation	1058968	<a href="https://www.pituitary.org.uk/">https://www.pituitary.org.uk/</a>
Platelet Society	1172202	<a href="https://plateletsociety.co.uk/">https://plateletsociety.co.uk/</a>
Police Community Clubs of Great Britain	N/A	<a href="https://www.policecommunityclubs.org/">https://www.policecommunityclubs.org/</a>
Polycystic Kidney Disease Charity	1160970	<a href="https://pkdcharity.org.uk/">https://pkdcharity.org.uk/</a>
Pompe Support Network	1186383	<a href="https://pompe.uk/">https://pompe.uk/</a>
Positively UK	1007685	<a href="https://positivelyuk.org/">https://positivelyuk.org/</a>
Primary Immunodeficiency UK	1193166	<a href="http://www.immunodeficiencyuk.org/">http://www.immunodeficiencyuk.org/</a>
Progress Educational Trust	1139856	<a href="https://www.progress.org.uk/">https://www.progress.org.uk/</a>
Progressive Supranuclear Palsy Association	1037087	<a href="https://pspassociation.org.uk/">https://pspassociation.org.uk/</a>
Prostate Cancer UK	1005541	<a href="https://prostatecanceruk.org/">https://prostatecanceruk.org/</a>
Psoriasis Association	1180666	<a href="https://www.psoriasis-association.org.uk/">https://www.psoriasis-association.org.uk/</a>
Pulmonary Hypertension Association UK	1120756	<a href="https://www.phauk.org/">https://www.phauk.org/</a>
Pumping Marvellous Foundation	1151848	<a href="https://www.pumpingmarvellous.org/">https://www.pumpingmarvellous.org/</a>
Rain Trust	N/A	<a href="https://www.nhs.uk/services/service-directory/rain-trust/N10972097">https://www.nhs.uk/services/service-directory/rain-trust/N10972097</a>
Rainbow Trust Children's Charity	1070532	<a href="https://www.rainbowtrust.org.uk/">https://www.rainbowtrust.org.uk/</a>
Rapid Effective Assistance For Children With Potentially Terminal Illness	802440	<a href="https://reactcharity.org/">https://reactcharity.org/</a>
Red Rose Recovery	1152474	<a href="https://redroserecovery.org.uk/">https://redroserecovery.org.uk/</a>
Release	801118	<a href="https://www.release.org.uk/">https://www.release.org.uk/</a>
Rethink Mental Illness	271028	<a href="https://www.rethink.org/">https://www.rethink.org/</a>
Retina UK	1153851	<a href="https://retinuk.org.uk/about/">https://retinuk.org.uk/about/</a>
Revive Multiple Sclerosis Support	SC022886	<a href="https://www.revivemssupport.org.uk/">https://www.revivemssupport.org.uk/</a>
Roy Castle Lung Cancer Foundation	1046854	<a href="https://roycastle.org/">https://roycastle.org/</a>
Royal Free Charity	1165672	<a href="https://royalfreecharity.org/">https://royalfreecharity.org/</a>
Royal National Institute of Blind People	226227	<a href="https://www.rnib.org.uk/">https://www.rnib.org.uk/</a>
Royal Osteoporosis Society	1102712	<a href="https://theros.org.uk/">https://theros.org.uk/</a>
Ruth Strauss Foundation	1183221	<a href="https://ruthstraussfoundation.com/">https://ruthstraussfoundation.com/</a>
Salivary Gland Cancer UK	1182762	<a href="https://www.salivaryglandcancer.uk/">https://www.salivaryglandcancer.uk/</a>
SANE	296572	<a href="https://www.sane.org.uk/">https://www.sane.org.uk/</a>
Sarcoma UK	1139869	<a href="https://sarcoma.org.uk/">https://sarcoma.org.uk/</a>
Scleroderma and Raynauds UK	1161828	<a href="https://www.sruk.co.uk/">https://www.sruk.co.uk/</a>
Scottish Drugs Forum	SC008075	<a href="https://www.sdf.org.uk/">https://www.sdf.org.uk/</a>

Scottish Families Affected by Alcohol & Drugs	N/A	<a href="https://www.sfad.org.uk/">https://www.sfad.org.uk/</a>
Scottish Huntington's Association	SC010985	<a href="https://hdscotland.org/">https://hdscotland.org/</a>
Shift.MS	1117194	<a href="https://shift.ms/">https://shift.ms/</a>
Shine Cancer Support	1146902	<a href="https://shinecancersupport.org/">https://shinecancersupport.org/</a>
Sickle Cell Society	1046631	<a href="https://www.sicklecellsociety.org/">https://www.sicklecellsociety.org/</a>
Skin Conditions Campaign Scotland	SC030004	<a href="https://www.disabilityscot.org.uk/organisation/skin-conditions-campaign-scotland/">https://www.disabilityscot.org.uk/organisation/skin-conditions-campaign-scotland/</a>
Society for Mucopolysaccharide Diseases	1143472	<a href="https://www.mpsociety.org.uk/">https://www.mpsociety.org.uk/</a>
Somerville Foundation	1138088	<a href="https://sfhearts.org.uk/">https://sfhearts.org.uk/</a>
Sophia Forum	1131629	<a href="https://sophiaforum.net/">https://sophiaforum.net/</a>
Spinal Muscular Atrophy Support UK	1106815	<a href="https://smauk.org.uk/">https://smauk.org.uk/</a>
St Elizabeths Centre	1176777	<a href="https://www.stelizabeths.org.uk/">https://www.stelizabeths.org.uk/</a>
Stroke Association	211015	<a href="https://www.stroke.org.uk/">https://www.stroke.org.uk/</a>
Swallows Head and Neck Cancer Charity	1149794	<a href="https://www.theswallows.org.uk/">https://www.theswallows.org.uk/</a>
Target Ovarian Cancer	1125038	<a href="https://targetovariancancer.org.uk/">https://targetovariancancer.org.uk/</a>
Tenovus Cancer Care	1054015	<a href="https://www.tenovuscancercare.org.uk/">https://www.tenovuscancercare.org.uk/</a>
Terrence Higgins Trust	288527	<a href="https://www.tht.org.uk/">https://www.tht.org.uk/</a>
Thrombosis UK	1090540	<a href="https://thrombosisuk.org/news/post.php?s=2021-10-11-thrombosis-uk-winner-of-activity-of-the-year-award-2021">https://thrombosisuk.org/news/post.php?s=2021-10-11-thrombosis-uk-winner-of-activity-of-the-year-award-2021</a>
Tiny Tickers	1078114	<a href="https://www.tinytickers.org/">https://www.tinytickers.org/</a>
Together for Short Lives	1144022	<a href="https://www.togetherforshortlives.org.uk/">https://www.togetherforshortlives.org.uk/</a>
TRACtion Cancer Support	SCO048145	<a href="https://www.tractioncancersupport.org/">https://www.tractioncancersupport.org/</a>
Trekstock	1132421	<a href="https://www.trekstock.com/">https://www.trekstock.com/</a>
Trevi	1075433	<a href="https://trevi.org.uk/">https://trevi.org.uk/</a>
Tuberous Sclerosis Association	1039549	<a href="https://tuberous-sclerosis.org/">https://tuberous-sclerosis.org/</a>
Turner Syndrome Support Society	1080507	<a href="https://tss.org.uk/">https://tss.org.uk/</a>
Twins Trust	1076478	<a href="https://twinstrust.org/">https://twinstrust.org/</a>
UK Breast Cancer Group	1177296	<a href="https://ukbcg.org/">https://ukbcg.org/</a>
UK Lung Cancer Coalition	N/A	<a href="https://www.uklcc.org.uk/">https://www.uklcc.org.uk/</a>
UK Primary Immune-deficiency Patient Support	1148789	<a href="https://ukpips.org.uk/">https://ukpips.org.uk/</a>
UK Thalassaemia Society	275107	<a href="https://ukts.org/">https://ukts.org/</a>
University of Newcastle Institute of Neuroscience	N/A	<a href="https://www.ncl.ac.uk/medical-sciences/research/research-themes/neuroscience/">https://www.ncl.ac.uk/medical-sciences/research/research-themes/neuroscience/</a>
Urology Cancer Research and Education	1120887	<a href="http://www.ucare-oxford.org.uk/">http://www.ucare-oxford.org.uk/</a>
Versus Arthritis	207711	<a href="https://www.versusarthritis.org/">https://www.versusarthritis.org/</a>
Waldenstrom's Macroglobulinaemia UK	1187121	<a href="https://wmuk.org.uk/">https://wmuk.org.uk/</a>
White Chapel Mission	227905	<a href="https://whitechapel.org.uk/">https://whitechapel.org.uk/</a>
Working with Cancer	9092152	<a href="https://workingwithcancer.co.uk/">https://workingwithcancer.co.uk/</a>
Young Epilepsy	311877	<a href="https://www.youngepilepsy.org.uk/">https://www.youngepilepsy.org.uk/</a>



### Inclusion/exclusion of patient organisations



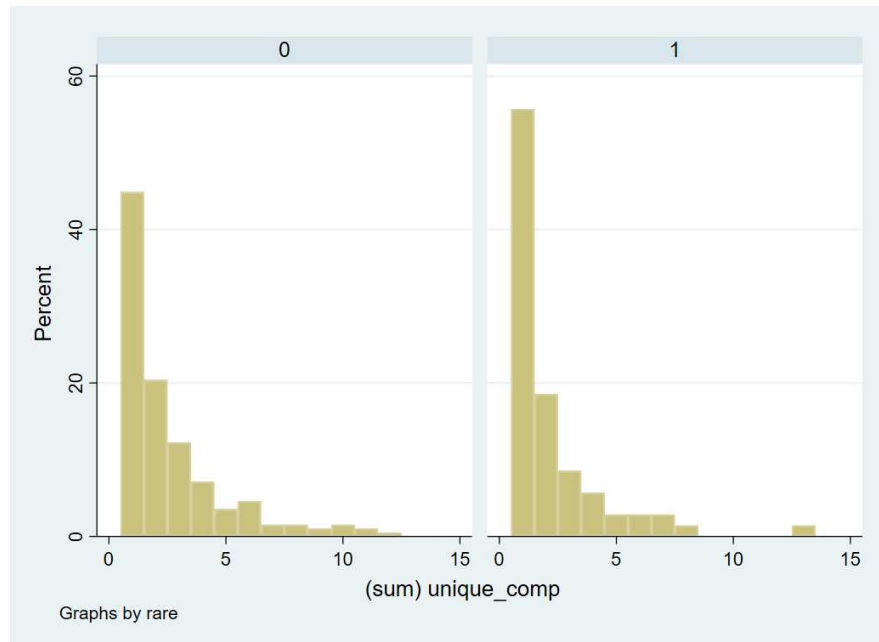
<sup>1</sup>Not aligned with geographical scope e.g. Irish, US-based

<sup>2</sup>Not aligned with EFPIA's definition of patient organisation

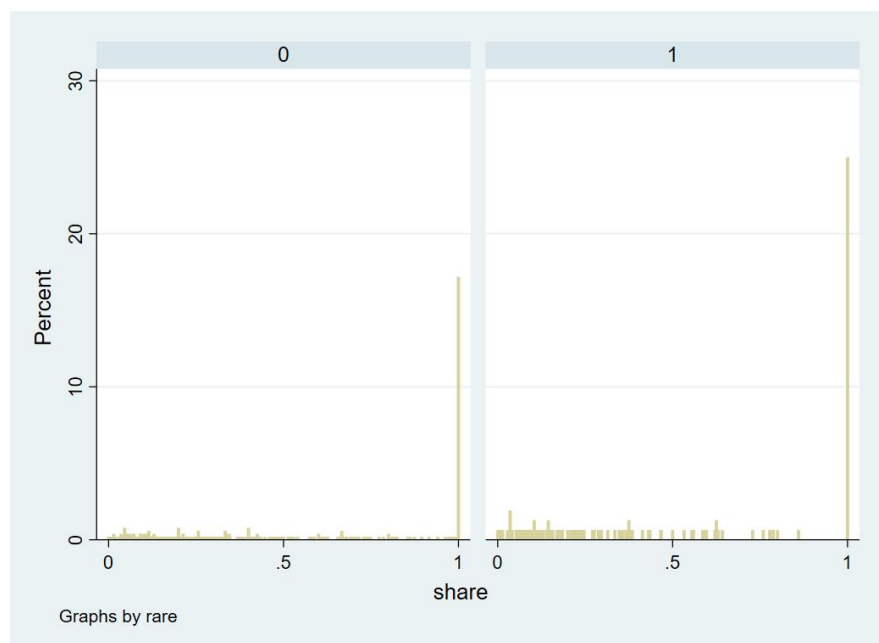
<sup>3</sup>Organisations for whose nature is unclear i.e. patient organisation website could not be identified

## Additional tables and figures

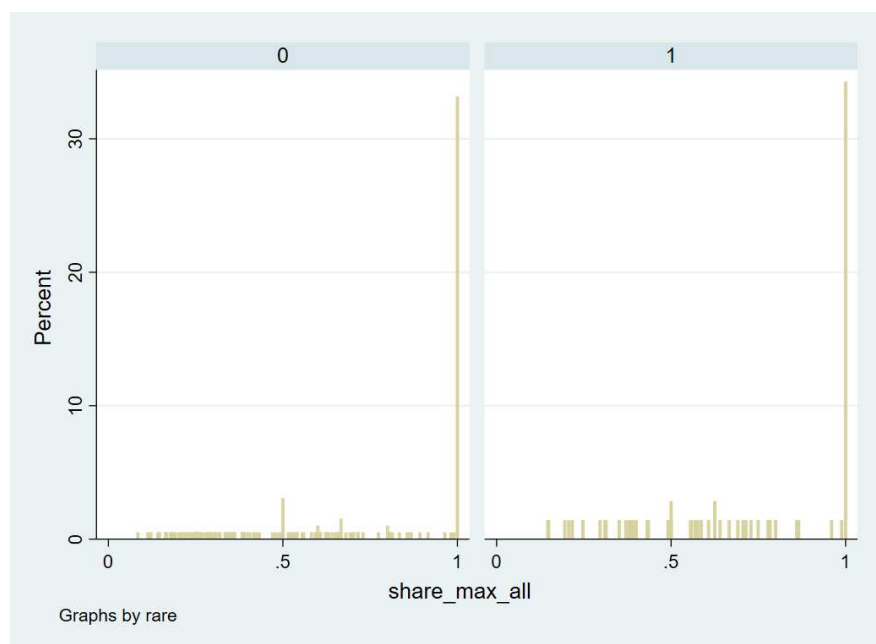
**Figure 2. Histogram of unique companies funding patient organisations in 2020, broken down by rarity of disease**



**Figure 3. Histogram of share of overall industry funding to patient organisations coming from each contributing company in 2020, broken down by rarity of disease**



**Figure 4. Histogram of share of industry funding of each organisation comprised by the single highest payment in 2020, broken down by rarity of disease**



## 1 Sub-group analyses

### 2 **Excluded patient organisations**

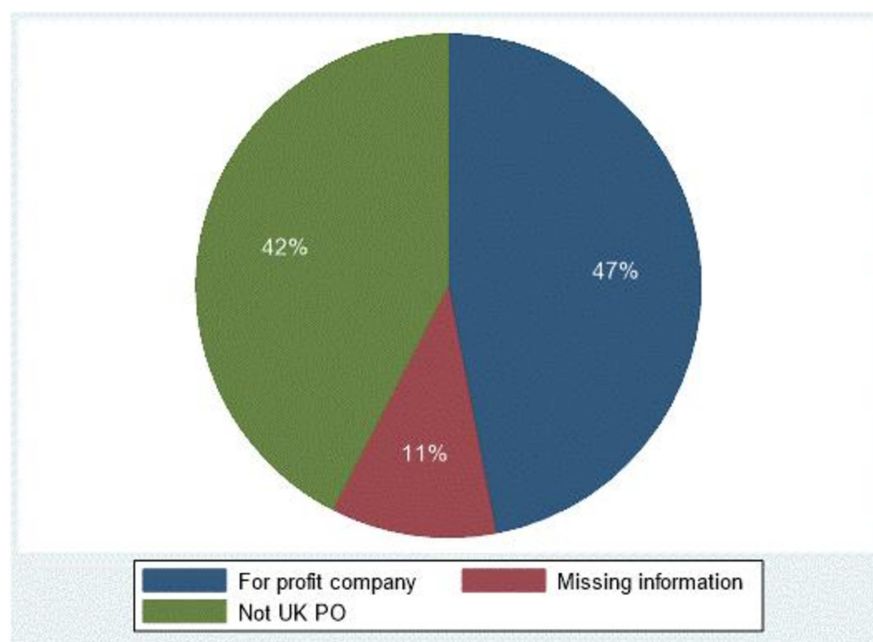
3 66 payments made 28 to patient organisations were excluded from the analysis as they did not  
4 match EFPIA's definition of "*not-for-profit organisations, mainly composed of patients and/or*  
5 *caregivers, that represent and/or support the needs of patients and/or caregivers*".

6 Figure 5 illustrates the reasons for patient organisations exclusion. Most of the excluded patient  
7 organisations were for profit organisations (47%; n=31), followed by not UK-based (42%;  
8 n=28) and organisations for which no information could be found online (11%; n=7).

9 Non-UK patient organisations mostly comprised international alliances of patient  
10 organisations, European or Irish organisations. We classified organisations as for-profit if they  
11 appeared in the UK government repository of companies<sup>1</sup> as *private limited companies*. Care  
12 homes, consultancies and rehabilitation clinics were the most prominent in this category.

13 Overall, payments to excluded patient organisations amounted to £869,677, about 4% of the  
14 included payments (Figure 6).

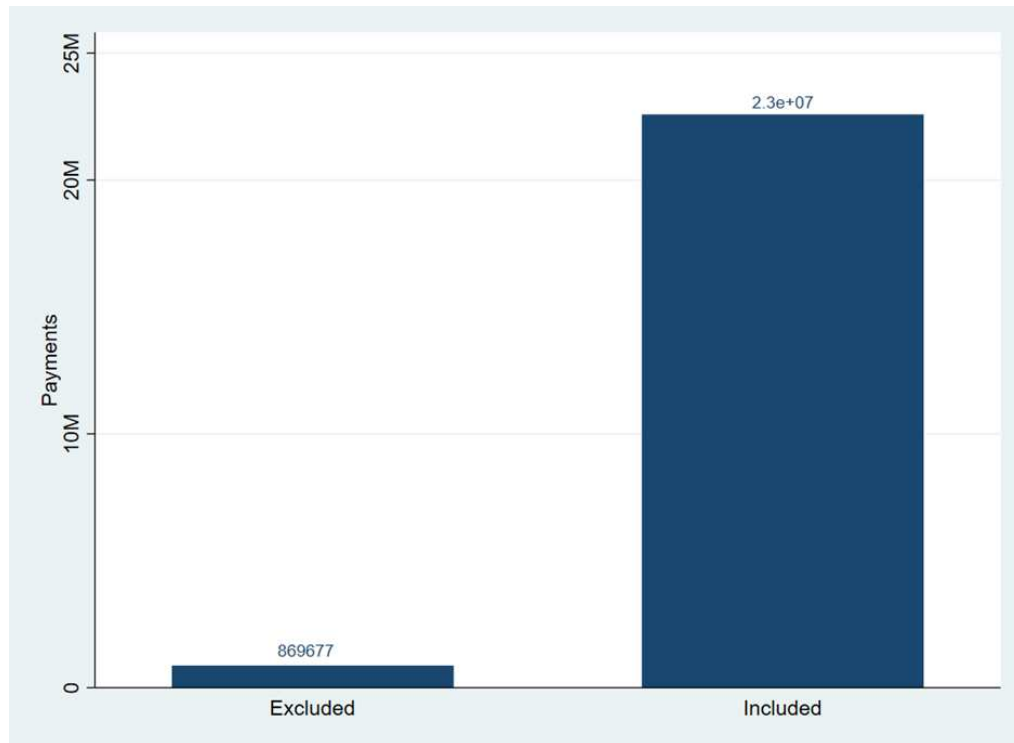
### 15 **Figure 5. Excluded patient organisations by reason of exclusion**



16

<sup>1</sup> <https://find-and-update.company-information.service.gov.uk/>

1 **Figure 6. Payments to included and excluded patient organisations**



2

3

## 1 References

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