

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.¹ 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.¹ 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),² 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.³

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.^{4 5} 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).⁶
 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.⁷ 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.⁸

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.

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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

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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*.

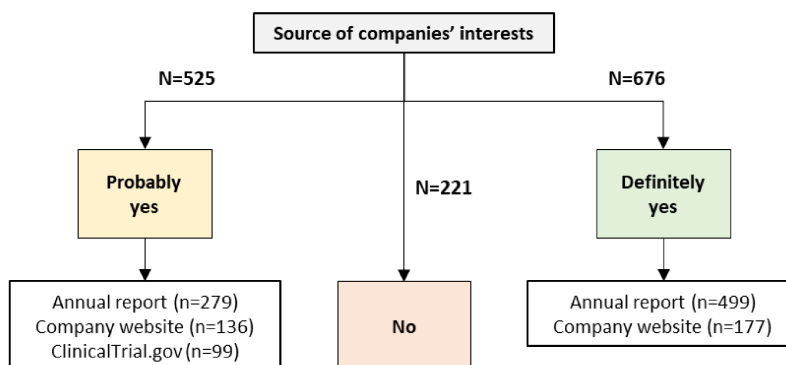
4 Subsequently, companies' annual reports, website and the ClinicalTrials.gov database were
5 searched to assess whether the each company had an interest in the condition supported by the
6 patient organisation receiving the payment. The diagram in the main document (Figure 1)
7 schematically illustrates 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.

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



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1 Variables cleaning and coding

2 Table 2. Description of key variables in payment database

Variables name	Description	Details
Company	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.
ABPI member	ABPI membership of company; <i>source: ABPI full members list</i>	0 = not ABPI member, 1 = ABPI member
Company_condition	Concatenation of company name and disease area targeted by the patient organisation	Concatenation used for coding and analysis purposes
Company interest	Whether the company hold an interest* in the condition targeted by the patient organisation	<ul style="list-style-type: none"> - Definitely yes: 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) - Probably yes: 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) - No : None of the above
Source	Source of company interest variable	Annual report, company website, ClinicalTrials.gov, none
Name of PO	Name of patient organization as reported by companies in disclosure report	-
Standardised PO name	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"> 1. Patient organisations' names for typos, abbreviations, spelling mistakes and duplicated within the companies' disclosures (e.g. Crohn's & Colitis UK and CCUK would both be standardized to Crohn's and Colitis UK); 2. If the patient organisation changed name over time, the latest name on record was used;

		<ol style="list-style-type: none"> 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); 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)
Reason for exclusion	Reason why the organisation was excluded from the analysis	<ul style="list-style-type: none"> - Not UK organisation (not aligned with geographical scope e.g. Irish, US-based); - For profit company (not aligned with definition of patient organization used in the study); - Missing information (organisations for whose nature is unclear i.e. patient organisation website could not be identified)
ICD-11	Classification of disease targeted by the patient organisation according to the WHO ICD-11; <i>source: ICD WHO website</i>	General classification (ICD-11 chapters) <i>See Excel file, Inputs tab</i>
Condition	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
Charity number (if any)	Charity number as reported in the organization website or as reported in the England and Wales Charity Commission website	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
Company number (if charity number missing)	Company number as reported in the organization website or as reported in the Government Company Information Service website 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
Link	Link of patient organisation website	-
Rare disease	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"> 1. The condition is listed in Orphanet list of rare diseases regardless of its ICD-11 level classification; 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)

Details of payment	Details of payment as reported by companies in disclosure report	-
Country	Country of payment	The country considered for the entire database is the UK
Year	Year of payment	2020
Currency	Currency of payment	Currency the payment is reported in the disclosure reports (i.e. EUR, GBP, USD, CHF, SEK, NKK)
Currency_year	Concatenation of currency and year of payment for conversion purposes	-
Value of payment	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
Value in 2020 pounds	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.

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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

Company	Company website only	HCOs database only	Both
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

LEO	X		
Lundbeck			X
Lupin	X		
MSD			X
Merck			X
Merz			X
Napp			X
Norgine		X	
Novartis			X
Novo Nordisk			X
Octapharma		X	
PTC	X		
Pfizer			X
Pharmasure		X	
Pierre Fabre			X
Recordati	X		
Roche			X
Rosemont			X
Sandoz		X	
Sanofi			X
Santen	X		
Seqirus	X		
Servier	X		
Shionogi		X	
Shire			X
Sobi	X		
Takeda			X
Teva		X	
Tillotts	X		
UCB			X
Valneva	X		
Veriton		X	
Vifor			X
Zogenix	X		
Total (n; %)	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**

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

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

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

Pierre Fabre	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0
Recordati	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Roche	0	1	0	0	0	0	1	0	0	1	1	0	0	0	1	0	0	0	0
Rosemont	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Sandoz	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Sanofi	1	1	1	1	1	0	1	0	1	0	0	1	1	1	0	0	0	0	0
Santen	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0
Seqirus	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Servier	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Shionogi	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Shire	0	0	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0
Sobi	0	1	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Takeda	0	1	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0
Teva	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Tillotts	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
UCB	0	0	1	0	0	0	1	0	0	0	0	1	1	0	0	0	0	0	0
Valneva	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Veriton	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Vifor	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Zogenix	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	https://www.nhs.uk/services/Careproviders/Overview/DefaultView.aspx?id=47011
Action Bladder Cancer UK	1164374	https://actionbladdercanceruk.org/
Action for Pulmonary Fibrosis	1152399	https://www.actionpf.org/
Action On Pre-Eclampsia	1013557	https://action-on-pre-eclampsia.org.uk/
Action on Smoking and Health - Wales	1120834	https://ash.wales/
Action Duchenne	1101971	https://www.actionduchenne.org/
Adfam	1067428	https://adfam.org.uk/
Africa Advocacy Foundation	1164778	https://www.africadvocacy.org/
African-Caribbean Leukaemia Trust	1119516	https://aact.org/
Age UK	1128267	https://www.ageuk.org.uk/
Alex - The Leukodystrophy Charity	1106008	https://www.alextlc.org/
ALK Positive Lung Cancer	1181171	https://www.alkpositive.org.uk/
Alkaptonuria Society	1101052	https://akusociety.org/
Allergy UK	1094231	https://www.allergyuk.org/
Alliance for Heart Failure	N/A	https://allianceforheartfailure.org/
Alzheimer Scotland	SC022315	https://www.alzscot.org/
Alzheimer's Support	1048314	https://www.alzheimerswiltshire.org.uk/
Alzheimer's Research UK	1077089	https://www.alzheimersresearchuk.org/
Alzheimer's Society	296645	https://www.alzheimers.org.uk/
Amyloidosis Patients Association	1183624	https://register-of-charities.charitycommission.gov.uk/charity-details/?regid=1183624&subid=0
Anthony Nolan	803716	https://www.anthonynolan.org/
Anticoagulation UK	1090250	https://register-of-charities.charitycommission.gov.uk/charity-details/?regid=1090250&subid=0
AOFAC Foundation	1162155	https://aofacfoundation.org/
Aplastic Anaemia Trust	1107539	https://www.theaat.org.uk/
APS Support UK	1138116	https://aps-support.org.uk/
Arthritis and Musculoskeletal Alliance	1108851	http://arma.uk.net/
Aspens	1171446	https://www.aspens.org.uk/
Association for Glycogen Storage Disease	1132271	https://agsd.org.uk/
Asthma + Lung UK	326730	https://www.asthma.org.uk/
Astriid	1176645	https://astriid.org/
Atrial Fibrillation Association	1122442	Supporting children terminally ill
Axial Spondylitis International Federation	1173902	https://asif.info/
Baby Lifeline	1006457	https://www.babylifeline.org.uk/
Bath Institute for Rheumatic Diseases	1040650	https://www.birdbath.org.uk/

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

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

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

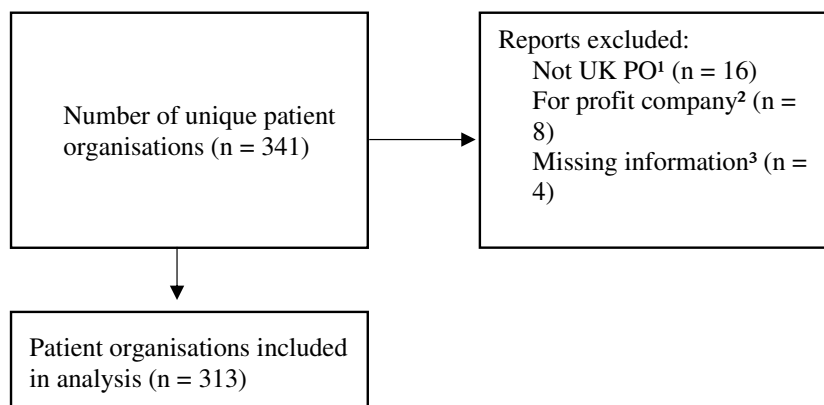
International Niemann-Pick Disease Alliance	1150256	https://www.inpda.org/
International Patient Organisation for Primary Immunodeficiencies	1058005	https://ipopi.org/
Invisible Cafe	N/A	https://theinvisiblecafe.co.uk/
Isabel Hospice Limited	1046826	https://www.isabelhospice.org.uk/
Jo's Cervical Cancer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

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

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

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

Inclusion/exclusion of patient organisations



¹Not aligned with geographical scope e.g. Irish, US-based

²Not aligned with EFPIA's definition of patient organisation

³Organisations 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

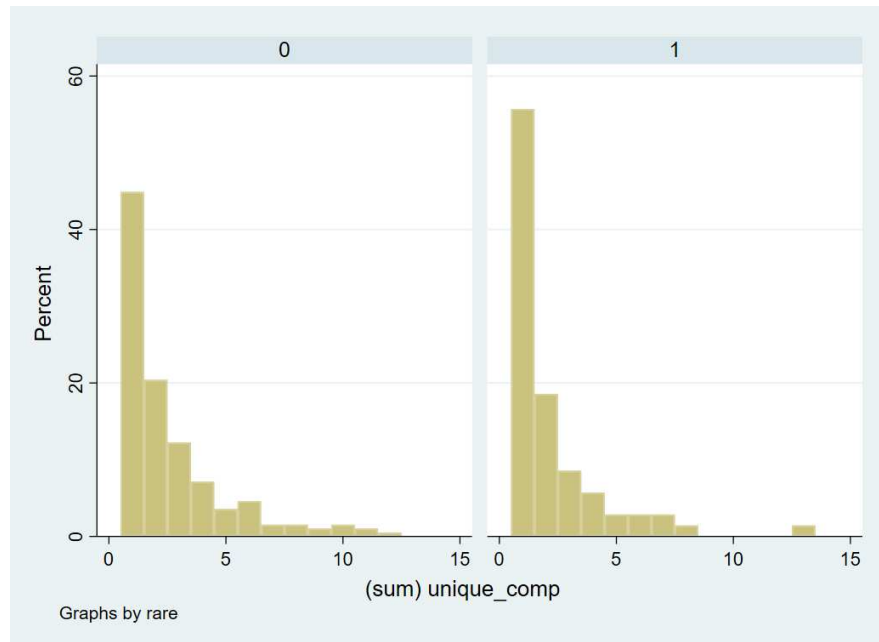


Figure 3. Histogram of share of overall industry funding to patient organisations coming from each contributing company in 2020, broken down by rarity of disease

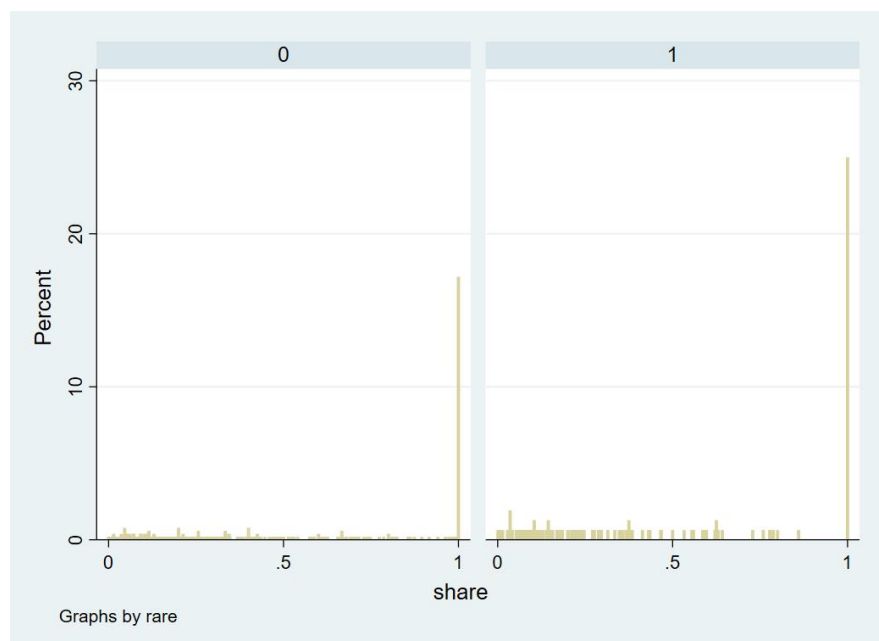
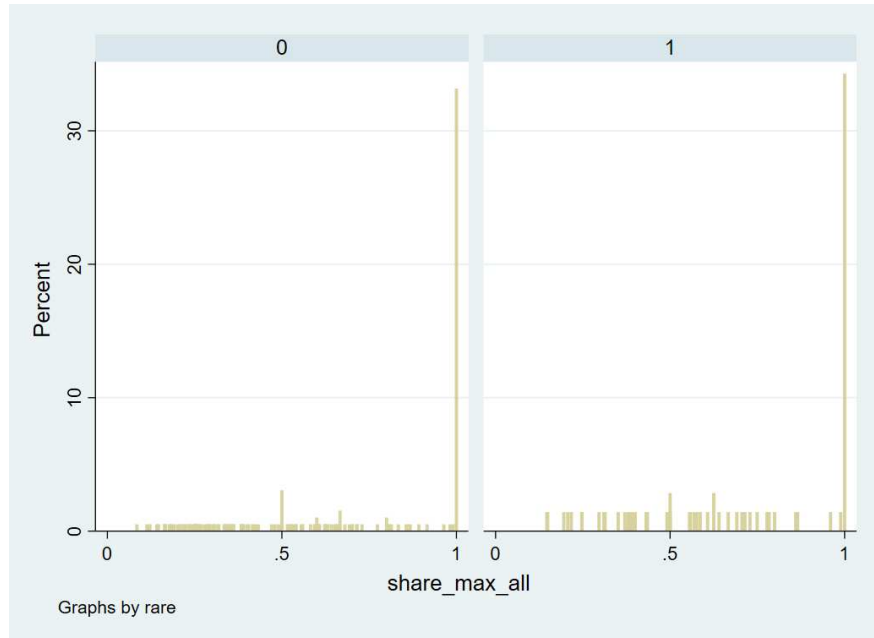


Figure 4. Histogram of share of industry funding of each organisation comprised by the single highest payment in 2020, broken down by rarity of disease



1 Sub-group analyses

2 **Excluded patient organisations**

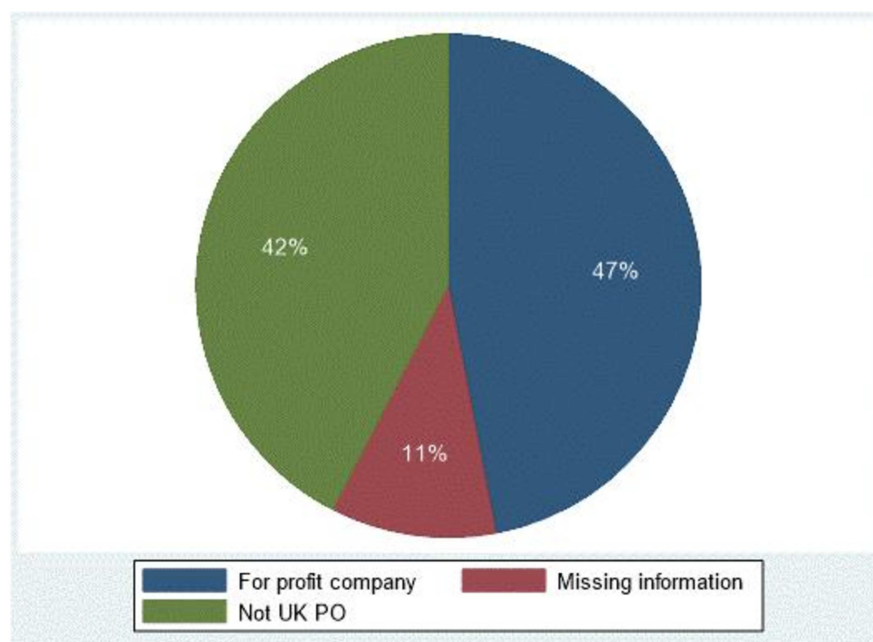
3 66 payments made 28 to patient organisations were excluded from the analysis as they did not
4 match EFPIA's definition of "*not-for-profit organisations, mainly composed of patients and/or*
5 *caregivers, that represent and/or support the needs of patients and/or caregivers*".

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 companies¹ 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).

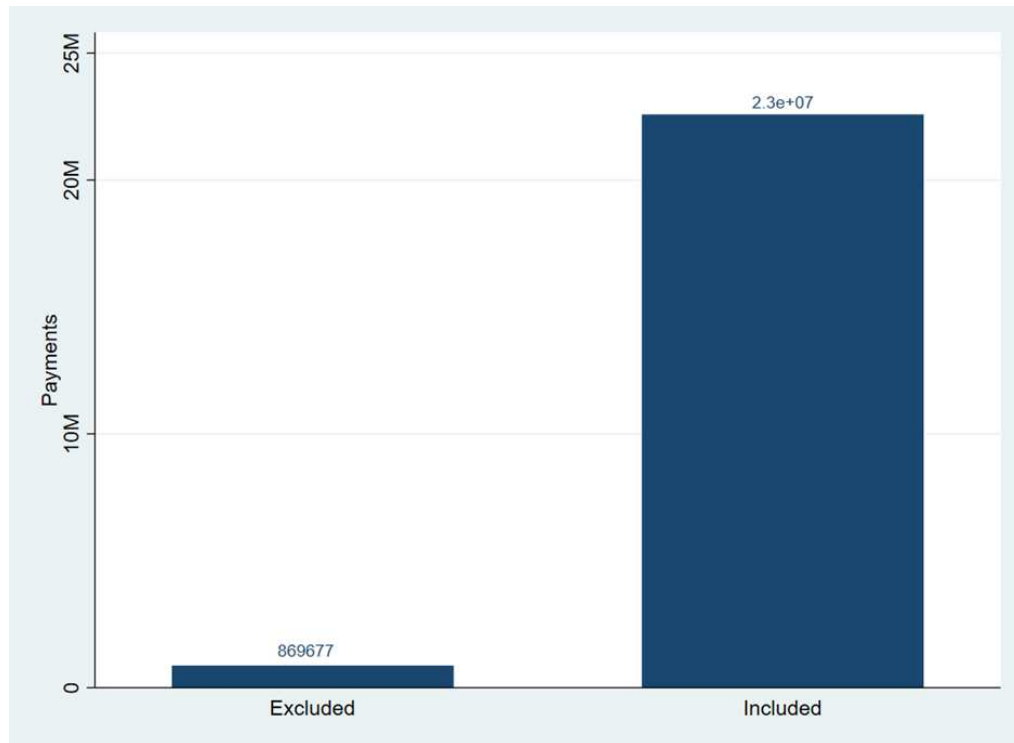
15 **Figure 5. Excluded patient organisations by reason of exclusion**



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

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



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1 References

- 2 1. PMCPA. ABPI Code of Practice 2021 [Available from: <https://www.pmcpa.org.uk/the-code/2021-interactive-abpi-code-of-practice/>.
- 3
- 4 2. Rickard E, Carmel E, Ozieranski P. Comparing pharmaceutical company payments in the four UK
5 countries: a cross-sectional and social network analysis. *BMJ Open* 2023;13(3):e061591. doi:
6 10.1136/bmjopen-2022-061591
- 7 3. Ozieranski P, Rickard E, Mulinari, Shai. Exposing drug industry funding of UK patient
8 organisations. *BMJ* 2019;365:11806. doi: 10.1136/bmj.11806
- 9 4. HMRC. HMRC yearly average and spot rates: HM Revenue and Customs; [Available from:
10 <https://www.gov.uk/government/publications/exchange-rates-for-customs-and-vat-yearly>.
- 11 5. HMRC. HMRC yearly average and spot rates: HM Revenue and Customs; 2022 [Available from:
12 <https://www.gov.uk/government/publications/exchange-rates-for-customs-and-vat-yearly>.
- 13 6. Orphanet. The portal for rare diseases and orphan drugs 2022 [Available from:
14 https://www.orpha.net/consor/cgi-bin/Disease_Search_Simple.php?lng=EN.
- 15 7. NICE. Policy on declaring and managing interests for NICE advisory committees, 2018.
- 16 8. WHO. ICD-11 for Mortality and Morbidity Statistics 2022 [Available from:
17 <https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/465177735?view=G0>.

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