



## ANALYSIS

# Exposing drug industry funding of UK patient organisations

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Drug company payment disclosures have limited transparency, but **Piotr Ozieranski and colleagues** find that they are increasing in value and are targeted at select patient organisations

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## Key messages

From 2012 to 2016 the drug industry donated over £57m (€65m; \$73m) to UK patient organisations, with the annual sum more than doubling over the period

The funding benefited a small number of organisations and activities related to research and public involvement

The industry gave priority to commercially high profile conditions

Industry payment disclosures had limited transparency

Patient organisations—third sector entities comprising patients, carers, or both, that provide support and advocate for people with specific conditions<sup>1,2</sup>—are increasingly involved in policy and research.<sup>1,3</sup> But their contributions have been questioned when they receive funding from drug companies.<sup>4,5</sup> With few exceptions,<sup>6,7</sup> existing research underscores that financial ties to an industry driven by profit risk turning patient organisations into seemingly independent “third parties”<sup>8–10</sup> that promote novel medicines, often with problematic clinical profiles, cost, or cost effectiveness.<sup>11,12</sup>

These concerns are crucial in the UK, where drug development, appraisals, and commissioning rely extensively on input from patient organisations.<sup>13</sup> Notably, patient organisations contributing to appraisals by the National Institute for Health and Care Excellence (NICE) have widespread, and often not entirely transparent, financial relationships with drug companies,<sup>14</sup> which is consistent with findings from other countries.<sup>4,5,15</sup>

We know little about the scale of industry funding, its main providers and recipients, and the nature of funded activities.<sup>16</sup> These questions have not been answered by case studies of policy decisions or patient organisations<sup>17</sup> or by cross sectional analyses of industry sponsorship using patient organisations’ websites,<sup>1,5</sup> tax records,<sup>5</sup> and surveys.<sup>4</sup> But new sources of data

generated by the industry offer new opportunities for analysis.<sup>1,14</sup> We use one such source, disclosure reports published on company websites,<sup>16,18</sup> combined with patient organisation websites and charity regulator records to examine the big picture of industry funding of UK patient organisations.

## Forming a new payment database

Since 2012 corporate members of the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the Association of the British Pharmaceutical Industry (ABPI) must disclose their payments to patient organisations. Unlike healthcare professionals, patient organisations cannot decline the publication of data on their payments.<sup>19</sup> As in the US,<sup>1</sup> the disclosure reports are dispersed on company websites, so establishing the scope of industry involvement for any patient organisation, let alone the overall pattern, is difficult.

During June 2017 to July 2018 we searched online for disclosures of payments to “patient organis(z)ations” or “patient groups” made by companies participating in the ABPI’s Disclosure UK database in 2015<sup>20</sup> (see web supplements 1 and 4)—the database covers payments to healthcare professionals and organisations.<sup>21</sup> Overall, we identified 220 disclosure reports covering payments from 2012 to 2016, excluding 27 duplicates (see web supplement 5).

The number of disclosing companies rose from 30 in 2012 to 54 in 2015, then dropped to 46 in 2016 (web supplement 2). The proportion of ABPI companies (as of January 2018) that disclosed rose from 45% (24/53) in 2012 to 66% (35/53) in 2016. Overall, 66 companies published at least one disclosure report over the five years, but only 21 did it every year; these figures were 43 and 19, respectively, for members of ABPI. A missing report may indicate no payments or a failure to disclose.

We extracted data to a single database, converting all 5232 identified payments to 2016 pounds (see web supplement 6).

After reading the payment descriptions and carrying out additional web searches using recipient names, we excluded four payments that were not made in 2012-16 (worth £10 040 out of a total £61 874 269 (0.02%)) and 656 (worth £4 558 976), that were not made to UK organisations meeting EFPIA's definition of a patient organisation (box 1; see web supplements 3 and 4). These payments might signify problems in defining patient organisations,<sup>2</sup> possibly combined with precautionary over-reporting of payments.

#### Box 1: Definition of patient organisation by the EFPIA<sup>16</sup>

Patient organisations are defined as not-for-profit organisations (including the umbrella organisations to which they belong), mainly composed of patients or caregivers that represent and/or support the needs of patients or caregivers

The challenges we encountered in building our database are similar to earlier concerns about the low transparency of reporting of industry payments by patient organisations.<sup>4 5 15 22 23</sup> They also coincide with deficiencies in the transparency of payments to healthcare professionals<sup>24</sup> and organisations from Disclosure UK.<sup>20 24 25</sup>

We coded the condition areas of 444 out of 508 identified patient organisations (87%) using *ICD-10 (International Classification of Diseases, 10th revision)*; the remaining 64 organisations focused on diseases or issues not included in *ICD-10*. We also coded payment goals based on iterative reading and aggregating of semantically similar payment descriptions. We coded the characteristics of patient organisations using their website data and records held by the Charity Commission for England and Wales, the Scottish Charity Regulator, or the Charity Commission for Northern Ireland. Two researchers conducted the coding, resolving differences through discussion.

## Little and large: trends in industry payments

Overall, industry disclosed 4572 payments worth £57 305 253 during 2012-16. This represented only a sixth of its funding for healthcare professionals and organisations (£340.3m) in 2015 alone.<sup>26</sup> Patient organisations, however, seemed increasingly important for drug companies. From 2012 to 2016, the yearly number and value of payments rose (table 1). For the 21 companies that disclosed consistently over the five years, the number of payments increased slightly (738 versus 772), but their value was 1.4 times higher (£10 838 391 versus £7 634 493).

The top five payments represented 20% of the total value (table 2). The value of the largest payments rose over time, with the share of the top 5% almost doubling from 33% (2014) to 65% (2016). But small payments were most common, with 50% being no larger than roughly £5000 annually. Small payments are potentially important, as findings from the US show that even smaller amounts might affect physicians' prescribing.<sup>27</sup>

## Dominance of big pharma

A few companies dominated the funding landscape, with the top 10 providing 69.2% of all funding (table 3). Most of the top 10 showed a shared understanding of what constitutes acceptable payment values, with similar interquartile ranges (except for Pfizer and Astellas, representing the low and high extremes) and maximum payments (except for Pfizer, Takeda, and Astellas, which had considerably larger highest payments). As with payments to healthcare professionals, the largest donors were "big pharma" companies.<sup>20</sup>

## Who received funding?

Out of all 508 identified patient organisations, 434 (85%), receiving £53 467 424 (93%), had a clear organisational form. Associations formed the largest proportion of these (173, 40%), followed by foundations or funds (61, 14%), trusts (58, 13%), and forums, groups, and networks (51, 10%). The corresponding funding shares were 35%, 29%, 8%, and 4%.

Furthermore, 444 of the patient organisations (87%), receiving £54 071 418 (94.4%), were registered charities, so they had to follow minimum transparency requirements, including publishing their financial accounts.<sup>28</sup> Consistent with the EFPIA's definition of patient organisations as "mainly composed of patients and/or caregivers,"<sup>16</sup> 482 organisations (95%), receiving £56 666 334.8 (98.9%), had members (including support groups or online forums) or supporters (including volunteers or friends).

Most funding (£47 466 806, 82.8%) went to 314 multipurpose organisations combining patient support with advocacy, policy involvement, awareness raising, or research. Conversely, the organisations focusing on just one of the two activities highlighted in EFPIA's definition<sup>16</sup>—"support" (87 organisations) and "representation," here understood as "advocacy," (69)—received just £2 732 019.0 (4.8%) and £5 467 917.0 (9.5%), respectively.

## What activities got funded?

The top funding priority was supporting patient organisations' engagement with outside audiences. Notably, public involvement, including "advocacy, campaigning, and disease awareness," "communication," and "policy engagement" attracted £17 860 574 (31.2%) (table 4). Similarly, engagement in research totalled £14 085 520 (24.6%), mainly because of two large grants received by Myeloma UK and Breast Cancer Now (see table 2). By contrast, support for patients attracted £3 381 030 (5.9%) and organisational maintenance and development, £1 613 061 (2.8%).

This hierarchy of funding goals might indicate that patient organisations have matured organisationally, so outside engagement is the key area of their empowerment.<sup>7</sup> An alternative interpretation would focus on the risks associated with the underinvestment of core organisational functions and using patients as "third parties" leveraging industry influence in areas like drug development and approvals,<sup>29</sup> health technology assessment,<sup>12</sup> and commissioning.<sup>11</sup>

## Commercial drivers?

In drug discovery, the industry prioritises investing in some conditions over others based on their commercial viability.<sup>30</sup> Cancer in particular has a privileged place.<sup>31</sup> Our data show a similar pattern: of the 30 condition areas (or their combinations), the top five accumulated £39 423 529 (68.8%), with neoplasms alone attracting 36.4% (table 5). The second category—endocrine, nutritional, and metabolic diseases—received 11.3%, and infectious and parasitic diseases 8.0%.

The hierarchy of funding within each condition area also reflected the industry's commercial priorities. In neoplasms, multiple myeloma attracted £7 495 729 (35.9%), followed by breast cancer (19.6%); 26 other types of cancer attracted less than 10% of funding. Diabetes received £3 741 181 (57.6%), the most of any endocrine, nutritional, and metabolic disease. The bulk of funding for certain infectious and parasitic diseases

went to HIV (37.4%) and viral hepatitis (23.6%). Importantly, the biggest donors in these condition areas have recently launched several high priced drugs. Key examples include Pfizer (palbociclib for breast cancer<sup>32</sup>), Takeda (ixazomib for myeloma<sup>33</sup>), Lilly (dulaglutide for diabetes<sup>34</sup>), Gilead (emtricitabine/tenofovir for HIV<sup>35</sup> and sofosbuvir/ledipasvir for hepatitis C<sup>36</sup>).

As in the US,<sup>4</sup> funding was concentrated on a few patient organisations within each condition area. Crucially, across all 30 condition areas the top recipient accumulated an average share of 65.6% of funding.

## Clearing the fog

The emerging picture of industry funding shows that companies might seek to use some patient organisations as “third parties” in reaching other audiences. Without necessarily determining the content of the funded activities, firms could shape the profiles of patient organisations through heavy investment in their external activities. This could then influence the public’s and policy makers’ perceptions, consistent with other industry marketing practices.<sup>29</sup> Importantly, both tiers of the industry’s payment strategy have demonstrable effect on clinical “key opinion leaders” (large payments)<sup>37</sup> and prescribers (small payments).<sup>38</sup>

The concentration of funding on certain types of organisations, activities, and conditions might reinforce inequalities between organisations with different budget sizes,<sup>2</sup> advocacy potential,<sup>39</sup> or representing conditions ascribed varying levels of “social value.”<sup>40</sup> Furthermore, given the weakness of public funding,<sup>41</sup> limited industry investment in patient organisations’ internal work, could affect their long term sustainability.

Nevertheless, following patterns identified elsewhere, financial relationships between many companies (especially non-big pharma) and patient organisations are sparse.<sup>45</sup> In any case, answering questions about the extent of industry influence requires examining how open different patient organisations are to accepting funding<sup>15</sup> or how much their priorities match those promoted by industry funding.<sup>10</sup>

But the picture is not fully clear, given the transparency shortcomings, which are similar to those found in other areas with industry self regulation.<sup>42</sup> Tackling them would require an integrated, regularly updated payment database with robust quality assurance policies. The ABPI is not currently considering such a database,<sup>43</sup> but it should at least introduce a standardised disclosure template, perhaps modelled on the one used for Disclosure UK.<sup>44</sup> A space to report that no payments were made would enable identification of those breaching their disclosure obligations.<sup>16</sup> Furthermore, a precise definition of patient organisations would help distinguish them from healthcare organisations, which should be reported separately in Disclosure UK.<sup>43</sup>

Responding to risks posed by the concentration of industry funding requires structural solutions,<sup>45</sup> such as a shared corporate funding pool detached from current commercial objectives or treatment areas or a programme of public grants including, for example, the expansion of the Health and Wellbeing Programme run by the Department of Health and Social Care, NHS England, and Public Health England. This would make for a more level playing field for patient organisations that cover currently underfunded condition areas or have weak industry links. Achieving this objective, however, might face barriers related to a long term decline in public funding available to patient groups, which, depending on specific Brexit arrangements, might be further exacerbated by loss of access to EU funding;

the increasingly complex institutional environment in which patient organisations operate; and a widening scope of patient organisations’ activity.<sup>41</sup>

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## Tables

**Table 1 | Drug industry payments to UK patient organisations, adjusted for inflation (2012-16)\***

Year	2012	2013	2014	2015	2016	All years
Value of payments (£)	8 179 426	6 974 258	9 076 723	12 110 650	20 964 196	57 305 253
No of payments	808	751	873	992	1148	4572
Median (interquartile range) payment	34 212 (526 to 10 521)	4114 (553 to 10 285)	5070 (913 to 12 676)	5050 (607 to 13 067)	3500 (500 to £10 091)	4500 (604 to 1 546)
No of drug companies†	30	40	47	52	45	64¶
No of patient organisations‡	229	231	260	283	277	508¶

\* All payments are expressed in 2016 GBP. We used the following values of the Consumer Price Index obtained from Office for National Statistics: 2012=96, 2013=98.2, 2014=99.6, 2015=100, 2016=101. †The numbers of drug companies are lower than the numbers of companies that published their disclosure reports because payments made by two companies were excluded from analysis (see supplementary data).

‡ The numbers of patient organisations take into account any rebranding (counted as one organisation) and mergers or takeovers (counted as separate organisations) in the period of observation (see supplementary data).

¶ Yearly numbers are not added as the same drug companies and patient organisations could provide or receive funding in more than one year.

Table 2| Top 10 drug industry payments to UK patient organisations (2012-16)

Drug company	Patient organisation	Value of payments in 2016 £ (year)	Payment description	Coding of payment goal
Takeda	Myeloma UK	5 924 160 (2016)	"Financial support and provision of investigational product for the conduct of an investigator initiated clinical trial in the Myeloma UK Clinical Trial Network."	Research
Pfizer	Breast Cancer Now	3 505 563 (2016)	"Pfizer began a three year research collaboration with the organisation's Catalyst programme. Catalyst is independently run by Breast Cancer Now and seeks to accelerate breast cancer research so that by 2050 no one else will die from breast cancer."	Research
Astellas	Bladder and Bowel Foundation*	1 025 150 (2015)	"Astellas has worked in collaboration with the Bladder and Bowel Foundation to develop a disease awareness TV advertising programme for overactive bladder."	Advocacy, campaigning, and disease awareness
Pfizer	Cancer Research UK	526 042 (2012)	"[W]e entered into a major £2m research partnership with CRUK and other partners."	Research
Pfizer	Cancer Research UK	484 800 (2015)	"We made a payment of fees relating to the second phase of the Stratified Medicines Partnership programme and the Matrix trial."	Research
Pfizer	Cancer Research UK	405 623 (2014)	"We made a payment of annual fees relating to the second phase of the Stratified Medicines Partnership programme."	Research
CSL Behring	Alpha-1 Alliance	308 554 (2013)	"Support for a disease awareness and education campaign."	Advocacy, campaigning, and disease awareness
Lilly	Alzheimer's Research UK	269 819 (2016)	"Contribution to the Dementia Consortium project 'Small Molecule induced regeneration for Parkinson's disease treatment'"	Research
Teva	Cystic Fibrosis Trust	245 084 (2016)	"Support for pharmacovigilance study services which included: R&D clinical conduct, clinical research organization professional fees, project management, registry access, and center grants for Imperial College London."	Research
AbbVie	Psoriasis Association	244 907 (2012)	"Non financial support"	Goal of funding unclear

\* Taken over by Bladder and Bowel Community in 2017.

Table 3| Top 10 funders of patient organisations (2012-16)

Company	Value of payments (£)	No of payments	Median (interquartile range) payment (£)	Largest single payment (£)
Pfizer	9 580 192	909	1029 (263 to 6072)	3 505 563
Takeda	6 614 468	55	3000 (1014 to 14 200)	5 924 160
Novartis	5 409 1990	447	7605 (758 to 15 255)	157 350
AbbVie	3 619 5350	289	4040 (655 to 13 466)	244 907
Lilly	3 284 206	258	2749 (447 to 16 178)	269 819
Astellas	2 928 978	88	12 741 (2035 to 30 225)	1 025 150
Sanofi	2 593 214	232	5025 (1034 to 14 324)	136 080
Bristol-Myers Squibb	1 929 615	248	4943 (849 to 10 521)	82 078
Celgene	1 867 877	133	5260 (1250 to 15 211)	111 546
MSD	1 813 144	253	3857 (514 to 9311)	95 100

Table 4| Top 10 payment categories according to their goals (2012-16)

Goal of funding*	Value (% of total) of payments (£)	No (%) of payments	Median (interquartile range) value (£)
Research	14 085 520 (24.6)	142 (3.1)	11 689 (5038 to 24 171)
Advocacy, campaigning, and disease awareness	8 272 590 (14.4)	496 (10.8)	7724 (2022 to 16 911)
Communication—media, meetings, online, publications	6 943 396 (12.1)	832 (18.2)	3042 (658 to 10 100)
Education and training	5 708 003 (10.0)	553 (12.1)	5260 (2000 to 12 850)
Patient support	3 381 030 (5.9)	214 (4.7)	10 120 (5000 to 17 386)
Project or programme funding (no specific goals stated)	3 002 251 (5.2)	153 (3.3)	12 500 (7084 to 24 240)
More than one distinct purpose mentioned	2 961 151 (5.2)	148 (3.2)	10 391 (5143 to 24 072)
Policy engagement	2 644 588 (4.6)	211 (4.6)	9 469 (4840 to 16 424)
Inputting to organisation's work through corporate membership, partnership, sponsorship, or support	2 082 891 (3.6)	175 (3.8)	10 000 (5260 to 13 677)
Organisational maintenance and development, including patient and volunteer engagement	1 613 0610 (2.8)	169 (3.7)	5070 (757 to 15 150)

\* The list of top 10 payment categories excludes 349 (7.6%) payments, worth £3 508 568 (6.1%), with an unclear goal.

**Table 5| Distribution of drug industry payments between and within condition areas (10 condition areas with the highest amount of funding, 2012-16)**

Condition areas based on ICD-10 categories *	Amount received (£) (% of total)	Distribution of payments within condition areas		
		No of organisations	Amount received (£) by top recipient (%)	Top recipient
Neoplasms	20 857 389 (36.4)	101	7 430 107 (35.6)	Myeloma UK
Endocrine, nutritional, and metabolic diseases	6 497 767 (11.3)	35	3 021 311 (46.5)	Diabetes UK
Certain infectious and parasitic diseases	4 585 142 (8.0)	60	1 022 603 (22.3)	Hepatitis C Trust
Diseases or issues not appearing in ICD-10	4 322 440 (7.5)	64	909 014 (21.0)	Heart UK
Diseases of the musculoskeletal system and connective tissue	3 160 790 (5.5)	24	902 728 (28.6)	National Ankylosing Spondylitis Society
Diseases of the nervous system	3 041 549 (5.3)	44	533 370 (17.5)	Multiple Sclerosis Trust
Diseases of the circulatory system	2 665 043 (4.7)	20	621 144 (23.3)	Atrial Fibrillation Association
Diseases of the digestive system; Diseases of the genitourinary system	2 307 771 (4.0)	3	2 271 217 (98.4)	Bladder and Bowel †
Mental and behavioural disorders	1 788 939 (3.1)	23	443 860 (24.8)	Alzheimer's Research UK
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	1 569 617 (2.7)	21	577 522 (36.8)	Haemophilia Society

\* The table excludes the 20 bottom ICD-10 condition areas and their combinations, which accumulated 11.4% of funding.

† Taken over by Bladder and Bowel Community in 2017