Appendix 1. Data collection – pharmaceutical industry payment disclosure reports

**Payments with the value of zero \*\*\*\*\***

Payments – *81* (1.9%)

Value - £*0* (0.0%)

Number of patient organisations – *9* (2.1%)

Number of drug companies – *1* (1.6%)

**Sample of drug companies – participants of Disclosure UK in 2015\*, \*\*, \*\*\***

ABPI members in 2018 - *53*

Non-ABPI members in 2018 - *55*

Total – *108*\*

**Sample of disclosure reports**

Number of reports (without duplicates) -

2012 – *30*; 2013 – *43*; 2014 – *47*; 2015 – *54*; 2016 – *46*

Total – *220*

**Sample of drug companies (donors)**

Number of companies disclosing payments in 2012 – *30*; 2013 – *43*; 2014 – *47*; 2015 – *54*; 2016 – *46*

Published reports at least once – *66*

**Sample of drug companies meeting inclusion criteria**

Payments – *5,232*

Value – *£61,874,305.0*

Number of organisations – *892*

Number of drug companies – *66*

**Sample of patient organisations meeting inclusion criteria**

Payments – *4,572*

Value – *£57,305,289.2*

Number of patient organisations – *489*

Number of drug companies – *64*

**Payments not made to UK patient organisations between 2012 and 2016 – exclusions\*\*\*\***

Payments – *660* (12.6%)

Value of payments - *£4,569,015.8* (7.4%)

Number of organisations – *403* (45.2%)

Number of drug companies – *2* (3.0%)

**Payments made to UK patient organisations not registered as charities – exclusions**

Payments – *256* (5.6%)

Value of payments - *£3,233,835* (5.6%)

Number of patient organisations – *64* (13.1%)

Number of drug companies – *1* (1.6%)

**Sample of patient organisations registered as charities**

Payments – *4,316*

Value – *£54,071,454.2*

Number of patient organisations – *425*

Number of drug companies – *63*

**Sample of patient organisations registered as charities receiving payments with values greater than zero**

Payments – *4,235*

Value – *£54,071,454.2*

Number of patient organisations – *416*

Number of drug companies – *62*

**Payments made to patient organisations with no income OR expenditure reported in any of the years from 2012 to 2016 OR patient organisations with pharmaceutical industry payments exceeding patient organisation income from 2012 to 2016 \*\*\*\*\*\***

Payments – *143* (3.4%)

Value - £*1,413,343.1* (2.6%)

Number of patient organisations – *1*8 (4.3%)

Number of drug companies– *0* (0.0%)

**Sample of patient organisations included in analysis**

Payments – *4,092*

Value – *£52,658,111.1*

Number of patient organisations – *398*

Number of drug companies – *62*

\* We assumed that a company participated in Disclosure UK in 2015 if it published its methodological notes on the Disclosure UK website in 2016 (methodological notes cover payments from the preceding year). The publication of methodological notes demonstrated that a company met the provisions of the ABPI Code of Conduct by disclosing its.

\*\* We carried out Google searches using the terms: “[Drug company name]” AND “patient organisation/patient organization/patient group”. If the search yielded no results we conducted supplementary searches on the company webpages.

\*\*\* Breakdown of companies into ABPI members and non-members is provided in Table 1

\*\*\*\* Detailed breakdown provided in Table 2

\*\*\*\*\* Detailed breakdown in Table 3 We excluded payments which did not have specific values to allow for accurate statistical analysis.

\*\*\*\*\*\* For a list of these organisations, including a detailed breakdown of these organisations see online Appendix 7-8

Table 1. Sample of drug companies – ABPI and non-ABPI members

|  |  |
| --- | --- |
| **ABPI member in 2018 – n=53** | **Non-ABPI member in 2018 – n=55** |
| A. Menarini | Accretio |
| Abbvie | Actavis |
| Actelion | Aegerion |
| Alexion | Aguettant |
| Alimera Sciences | Alcon |
| ALK-Abelo | AMCo |
| Allergan | ApoPharma |
| Alliance | Astellas |
| Almirall | Baxalta |
| Amgen | Baxter |
| AstraZeneca | Besins |
| Bausch and Lomb | BGP Products |
| Bayer | Bio Products Laboratory |
| Biogen | Biotest |
| BioMarin | Bracco |
| Bristol-Myers Squibb | Britannia |
| Boehringer Ingelheim | CEB Pharma |
| Celgene | Consilient Health |
| Chiesi | CSL Behring |
| Chugai | Dermal |
| Daiichi Sankyo | Diurnal |
| Eisai | Ferring |
| Lilly | Flynn Pharma |
| Fresenius Medical Care | Fresenius Kabi |
| Grünenthal | Galen |
| GSK | Gedeon Richter UK |
| Ipsen | Genzyme Therapeutics |
| Janssen | Gilead |
| LEO Pharma | Guerbet |
| Lundbeck | Hospira UK |
| Merck | HRA Pharma |
| Mitsubishi Tanabe Pharma | Jazz Pharmaceuticals |
| MSD | Martindale Pharma |
| Napp Pharmaceuticals | Meda Pharmaceuticals |
| Norgine | Merz Pharma |
| Novartis | Mundipharma International |
| Novo Nordisk | Nicovations |
| Orion Pharma | Octapharma |
| Otsuka Pharmaceuticals | Orphan Europe |
| Pfizer | Profile Pharma |
| Pharma Mar | PTC Therapeutics |
| Pierre Fabre Ltd | RB |
| Quintiles Commercial (Novex) | Rosemont Pharmaceuticals |
| Roche Products | Sandoz |
| Sanofi | Sanofi Pasteur |
| Santen | Sigma Tau Rare Diseases |
| Servier Laboratories | Sobi |
| Shionogi Europe | Special Products |
| Shire | STD |
| Sunovion Pharmaceuticals | Stirling Anglian |
| Takeda | Syner-Med |
| UCB | Teva |
| Vifor Fresenius Medical Care Renal Pharma | Thea Pharmaceuticals |
|  | Tillotts |
|  | Vifor Pharma Group |

Table 2. Breakdown of exclusions - payments not made to UK patient organisations between 2012 and 2016

|  |  |  |  |
| --- | --- | --- | --- |
| **Reason for exclusion** | **Number of payments (%)** | **Value of payments - £ (%)** | **Number of organisations (%)** |
| Outside period of observation | 4 (0.6) | 10,039.8 (0.2) | 0 (0.0) |
| Not an organisation | 14 (2.1) | 94,736.1 (2.1) | 0 (0.0) |
| More than one organisation | 17 (2.6) | 354,390.0 (7.8) | 0 (0.0) |
| Organisation - nature unclear | 57 (8.6) | 397,240.6 (8.7) | 39 (9.7) |
| Not a UK organisation | 54 (8.2) | 716,044.0 (15.7) | 30 (7.4) |
| *Excluded UK organisations* |  |  |  |
| Public sector – state organisation | 12 (1.8) | 18,629.7 (0.4) | 7 (1.7) |
| Public healthcare provider | 242 (36.7) | 726,401.4 (15.9) | 176 (43.7) |
| Private sector organisation | 47 (7.1) | 981,886.2 (21.5) | 33 (8.2) |
| University | 14 (2.1) | 86,670.3 (1.9) | 7 (1.7) |
| Professional organisation (third sector) | 143 (21.7) | 984,935.1 (21.6) | 73 (18.1) |
| Community interest company or social enterprise - healthcare provider (third sector) | 3 (0.5) | 2,690.7 (0.1) | 3 (0.7) |
| Healthcare provider (third sector) | 20 (3.0) | 46,522.0 (1.0) | 10 (2.5) |
| Not focusing directly on health (third sector) | 30 (4.5) | 148,396.5 (3.2) | 24 (6.0) |
| Community interest company or social enterprise - not focusing directly on health (third sector) | 3 (0.5) | 433.4 (0.0) | 1 (0.2) |
| Total | 660 (100) | 4,569,015.8 | 403 (100) |

Table 3. Breakdown of excluded payment with the value of zero

|  |  |
| --- | --- |
| **Reason for exclusion** | **Number of payments (%)** |
| Payment value was given as zero | 25 (30.9) |
| payment value was not provided | 9 (11.1) |
| Payments described as in-kind/non-financial support | 47 (58.0) |
| Total | 81 (100) |

Note. Under Clause 27 of the ABPI Code, companies must make publicly available each year a list of the patient organisations to which they provide support (both financial and significant non-financial), with a description of what that support is for, and the monetary value.