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An underreported relationship: a comparative study of pharmaceutical industry and patient organisation payment disclosures in the UK (2012-2016)

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4 An underreported relationship: a
5 comparative study of pharmaceutical
6 industry and patient organisation
7 payment disclosures in the UK (2012-
8 2016)
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Abstract

Objectives: To examine the underreporting of pharmaceutical company payments to patient organisations by donors and recipients.

Design: Comparative descriptive analysis of payments disclosed on drug company and charity regulator websites.

Setting: UK.

Participants: 87 donors (drug companies) and 425 recipients (patient organisations) reporting payments in 2012-2016.

Main outcome measures: Number and value of payments reported by donors and recipients; differences in payments from/to the same donors and recipients; payments reported in either dataset but not the other one; agreement between donor-recipient ties established by payments; overlap between recipient and donor lists and, respectively, patient organisation and industry data.

Results: Of 87 donors, 63 (72.4%) reported payments but 84 (96.6%) were mentioned by recipients. Although donors listed 425 recipients, only 200 (47.1%) reported payments. The number and value of payments reported by donors were 259.8% and 163.7% greater than those reported by recipients, respectively. The number of donors with matching payment numbers and values in both datasets were 3.4% and 0%, respectively; for recipients these figures were 7.8% and 1.9%. There were 24 and 3 donors missing from industry and patient organisation data during the entire study period, representing 38.1% and 3.6% of those in the respective datasets. The share of donor-recipient ties in which industry and patient organisation data agreed about donors and recipients was 38.9% and 68.4% in each dataset, respectively. Of 63 donors reporting payments, only 3 (4.8%) had their recipient lists fully overlapping with patient organisation data. Of 200 recipients reporting industry funding, 102 (51.0%) had their donor lists fully overlapping with industry data.

Conclusions: Both donors and recipients underreported payments. Existing donor and recipient disclosure systems cannot manage potential conflicts of interest associated with industry payments. Increased standardisation could limit the underreporting by each side but only an integrated donor-recipient database could eliminate it.

Strengths and limitations

- We examine the underreporting of pharmaceutical industry payments to patient organisations using large samples of donors and recipients over a period of time.
- We systematically compare the underreporting by donors and recipients using five complementary measures at different levels of analysis
- One key limitation is that the samples of donors and recipients were not exhaustive

- The full extent of underreporting remains unknown as no definitive list of payments exists

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Introduction

Many patient organisations accept funding from drug companies. A recent UK analysis showed that the industry donated over £57m (€65m; \$73m) to 508 patient organisations, with the annual sum more than doubling from 2012 to 2016.¹ Another study of 289 US patient organisations found that 156 (67%) received funding from for-profit companies, with a median proportion of 45% of their income coming from drug, medical device, or biotechnology companies.² Although industry funding may benefit patient organisations,^{3 4} it raises concerns about potential conflict of interests compromising patient organisations' independence and credibility.^{5 6 7 8 9}

In responding to these concerns, both donors¹⁰ and recipients⁴ assert that any conflict of interests can be managed by careful disclosure of funding. On the donor side, since 2012 members of pharmaceutical industry trade groups in European countries,¹¹ such as the Association of the British Pharmaceutical Industry (ABPI), have disclosed payments to patient organisations annually on each company's website, including their monetary value and purpose.¹² In the UK, the number of companies subscribing to the ABPI Code, and therefore committing to the disclosure of payments to patient organisations, also includes over sixty non-members of the ABPI; hence, nearly every relevant company is covered.¹³ However, the self-regulatory approach to payment disclosure has major shortcomings, including absent reports, unclear or inadequate payment descriptions, and unstandardised reporting.^{1 14} Likewise, on the recipient side, disclosures published on patient organisations' websites have been criticised as incomplete or uninformative.^{15 16 17 18 19} In the UK, a possibly more reliable, yet rarely examined,^{14 20} source of disclosures are mandatory annual accounts of patient organisations registered as charities with an annual income over £25,000. These accounts serve a dual-purpose of detailing the charity's activities and ensuring financial transparency by listing sources of income and how income is spent.

Notwithstanding the shortcomings of each side's disclosures, and the potentially complementary information they provide, donor and recipient disclosures are rarely compared. One exception is a recent UK study which identified companies not disclosing payments to patient organisations being mentioned in their annual accounts as donors.¹⁴ Another UK study found discrepancies between annual accounts of some patient organisations contributing to health technology assessment in England and drug company payment disclosures.²⁰ More broadly, cross-interrogation of different data sources has revealed undisclosed industry ties among treatment guideline panellists,^{21 22 23} clinical trialists, authors of medical journal articles,^{24 25 26 27 28} and some clinical commissioning groups²⁹ and NHS trusts in England.³⁰

We examine the underreporting of payments to UK patient organisations from 2012 to 2016 by comparing payment disclosures made by 87 companies to 425 patient organisations with the annual accounts of the same set of patient organisations. Specifically, by considering the extent to which the industry and patient organisation disclosures differ in information about who provided and received funding, and how much was paid and received, we examine the reliability of the two disclosures systems said to neutralise concerns about conflict of interests.

Methods

Data sources and extraction

Our sample of drug companies comprised all 108 participants of Disclosure UK in 2015, including 53 ABPI members (web supplement 1). Disclosure UK is a self-regulatory initiative covering payments to healthcare organisations³¹ and professionals,³² but because its participants subscribe to the ABPI Code, they should also separately disclose, on their websites, payments to patient organisations.¹⁻¹⁴ In June 2017 and January 2018, ER searched the company websites, identifying 220 disclosure reports published between 2012 and 2016. ER downloaded them and extracted payment data into a single Excel spreadsheet, converting all payment values to 2016 sterling. There were 66 (61.1%) companies disclosing payments in at least one year during this period. Following the exclusion of ineligible payments based on their timing or recipient characteristics, we established that 64 companies reported 4,572 payments, worth £57,305,289.2 to 489 UK patient organisations (web supplement 1).

In September 2017 and July 2018, ER searched for these organisations on the websites of the UK charity regulators – the Charity Commission for England and Wales, the Scottish Charity Regulator and the Northern Irish Charity Regulator – to which registered charities must submit their annual accounts. We considered accounts from financial years ending in 2012 to 2017 to cover all calendar year data from drug company reports. We found that 425 (86.9%) patient organisations drug companies listed as recipients published their annual accounts at least once with at least one charity regulator. In industry data, 63 (98.4%) companies reported 4,316 (94.4%) payments, worth £54,071,454.21 (94.4%) to these patient organisations.

ER read all annual accounts and extracted any information pertaining to drug company payments to an Excel spreadsheet. As with industry data, if several values were mentioned in a single payment description they were considered as separate payments. As patient organisation yearly accounts lack specific monthly end date,²⁰ we turned those covering months up to June into the previous calendar year, and the rest into the current calendar year. The 425 patient organisations registered as charities reported 4,372 payments, worth £58,668,293.6, from 167 donors. Following exclusion criteria referring to donor and recipient characteristics as well as the conversion of financial into calendar years (web supplement 2), we established that 200 (47.1%) organisations reported 1,661 (38.0%) payments, worth £33,037,955.8 (56.3%), from 84 (47.1%) drug companies. In particular, we excluded 2,014 payments, worth £1,992,147.3, made by 61 companies found in patient organisation data but missing from the original sample of Disclosure UK participants.

ER and PO checked the details of the data extraction. Any exclusions of payments were agreed.

The ethical implications of this study article were approved via a peer ethics review process at the Department of Social and Policy Sciences, University of Bath in April 2016. This study did not

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3 require a full ethical approval as it relied on publicly available data aggregated at the
4 organisational level.
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6 7 Analysis

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9 MC and PO converted the data into donor-recipient matrices and analysed it descriptively in
10 Excel. We examined the overall pattern of the number and value of payments in each
11 dataset and its changes over time. To provide further context for the reported results we
12 present additional data as web supplements (3-20) throughout the article [*Please note that*
13 *these web supplements are only available in the Excel file format and therefore could not be*
14 *uploaded as part of the online submission; we will provide them via email when requested by*
15 *the Editorial Office*].
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19 Outcome measures

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22 Absent an exhaustive list of payments, enabling a direct comparison of industry and patient
23 organisation data, we studied underreporting with five complementary measures.
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26 First, we compared the overall volume of payments reported in industry and patient
27 organisation data, including payments lacking specific values.
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30 Second, we examined the absolute and relative differences in payments reported in relation
31 to the same donors and recipients in industry and patient organisation data. We calculated
32 the absolute difference as the difference between the number/value of payments reported in
33 the two datasets; the relative difference was the absolute difference divided by the
34 number/value of payments in the dataset with the higher number/value of payments. To
35 compare larger and smaller donors and recipients we considered absolute and relative
36 differences at different thresholds of the overall number (i.e. ≥ 1 , >1 , >10 , >100 in at least one
37 dataset) and value of payments (i.e. $>£0$, $>£10,000$, $>£100,000$ in at least one dataset).
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41 Third, focusing on the highest relative differences, in which donors or recipients were present
42 in one but absent from the other dataset, we calculated the number and value of payments
43 related to donors and recipients missing from each dataset.
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46 Fourth, we compared the extent to which industry and patient organisation data conveyed
47 the same pattern of connections between donors and recipients. Specifically, we analysed
48 the overlap of ties (or connections) between donors and recipients – established by the
49 presence of payments – in each dataset.
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52 Finally, building on the analysis of donor-industry ties at the level of the two datasets, we
53 moved to the donor and recipient level by examining the extent of overlap between recipient
54 and donor lists in patient organisation and industry data, respectively.
55

56 Patient and public involvement

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58 No patients were involved in this study.
59
60

Results

Overview of industry and patient organisation data

Although 63 donors reported payments, 84 were mentioned by recipients. In industry data, donors disclosed payments to 425 recipients but only 200 (47.1%) of those reported payments during the study period (Table 1).

The number of payments disclosed by donors was 259.8% greater than those disclosed by recipients (Table 1). Each side was disclosing more payments over time, but the increase from 2012 to 2016 was greater in industry data (141.2% v 115.8%, respectively). In industry data, 4,235 (98.1%) payments reported by 62 (98.4%) donors to 416 (97.9%) recipients had values greater than 0. In patient organisation data, only 772 (46.5%) payments reported by 121 (60.5%) recipients from 62 (73.8%) donors had values greater than 0. The value of payments disclosed by donors was 163.7% higher than those disclosed by recipients. Over the five-year period the value of payments reported by donors increased by 257.6%, while those by recipients – by 434.7%.

Table 1 Patterns in payments reported by donors and recipients

| | All years | 2012 | 2013 | 2014 | 2015 | 2016 |
|--|--------------|-------------|-------------|-------------|--------------|--------------|
| Calculations based on the number of payments | | | | | | |
| Number of payments - industry data | 4316 | 769 | 706 | 821 | 934 | 1086 |
| Number of payments - patient organisation data | 1661 | 291 | 326 | 346 | 361 | 337 |
| Number of drug companies with at least one payment - industry data | 63 | 30 | 38 | 45 | 51 | 44 |
| Number of drug companies with at least one payment - patient organisation data | 84 | 56 | 65 | 65 | 69 | 65 |
| Number of patient organisations with at least one payment - industry data | 425 | 197 | 198 | 225 | 244 | 244 |
| Number of patient organisations with at least one payment - patient organisation data | 200 | 103 | 102 | 116 | 126 | 117 |
| Calculations based on the value of payments | | | | | | |
| Number of payments with value >£0 - industry data | 4235 | 748 | 682 | 813 | 915 | 1077 |
| Number of payments with value >£0 - patient organisation data | 772 | 144 | 148 | 144 | 173 | 163 |
| Value of payments - industry data (2016 £) | 54,071,454.2 | 7,797,600.4 | 6,189,152.7 | 5,583,101.6 | 11,415,293.2 | 20,086,306.3 |
| Value of payments - patient organisation data (2016 £) | 33,037,955.8 | 3,459,605.6 | 4,414,328.4 | 3,301,728.3 | 4,825,091.2 | 15,037,202.3 |
| Number of drug companies with at least one payment with the value >£0 - industry data | 62 | 30 | 38 | 45 | 50 | 44 |
| Number of drug companies with at least one payment with the value >£0 - patient organisation data | 62 | 42 | 44 | 42 | 46 | 44 |
| Number of patient organisations with at least one payment with the value >£0 - industry data | 416 | 197 | 193 | 225 | 237 | 244 |
| Number of patient organisations with at least one payment with the value >£0 - patient organisation data | 121 | 57 | 51 | 58 | 72 | 57 |

Record of the same donors and recipients in industry and patient organisation data

Having considered the overall pattern of payments, we now compare those reported in relation to the same donors and recipients in each dataset.

Donors

Of the 87 donors identified in industry and patient organisation data, three (3.4%) had matching payment numbers, and 49 (56.3%) had more payments in patient organisation data (Table 2; web supplement 3). In relative terms, only 21 (24.1%) donors had a difference in the number of payments less than 50%, and 27 (31.0%) had a difference of 100%, equivalent to only either donors or recipients reporting payments.

In both datasets, 74 (85.1%) donors had payment values greater than 0 (web supplement 3). Of those, 48 (64.9%) had a higher payment value in industry data and the remaining ones – in patient organisation data. Only 14 (18.9%) donors with payment values greater than 0 had a relative difference lower than 50%, while 24 (32.4%) donors had a relative difference of 100%.

Overall, donors with a high overall number and value of payments in either dataset typically had high absolute differences (web supplement 3). Contrastingly, donors with a small number or value of payments usually had higher relative differences, that is, high relative differences often resulted from few payments or payments of small value in one dataset but none in the other.

Over time, there was little improvement in the shares of donors with matching numbers of payments (from 1.6% in 2012 to 5.5% in 2016); the share of donors with matching payment values showed no improvement (0%). However, the shares of those with relative differences in payment numbers or values lower than 50% increased (from 11.5 to 17.4%; and from 7.7% to 25.5%, respectively) (web supplement 4).

Table 2 Donors – absolute and relative differences in the number and value of payments

| | All years | % |
|---|-----------|-------|
| Calculations based on the number of payments - absolute differences | | |
| Number of drug companies with at least one payment in at least one dataset - industry and patient organisation data | 87 | |
| Number of drug companies with exact match in both datasets | 3 | 3.4% |
| Number of drug companies with more payments in industry data | 49 | 56.3% |
| Number of drug companies with more payments in patient organisation data | 35 | 40.2% |
| Highest absolute difference between patient organisation and industry data - number of payments higher in industry data | 757 | |
| Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data | 53 | |
| Calculations based on the number of payments - relative differences | | |
| Number of drug companies with relative difference <10% | 5 | 5.7% |
| Number of drug companies with relative difference <20% | 9 | 10.3% |
| Number of drug companies with relative difference <50% | 21 | 24.1% |
| Number of drug companies with relative difference = 100% | 27 | 31.0% |
| Calculations based on the value of payments - absolute differences | | |
| Number of drug companies with at least one payment with value >£0 in at least one dataset | 74 | 100% |
| Number of drug companies with exact match in both datasets | 0 | 0.0% |
| Number of drug companies with higher payment value in industry data | 48 | 64.9% |
| Number of drug companies with higher payment value in patient organisation data | 26 | 35.1% |

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| 4 | Highest absolute difference between patient organisation and industry data - number of payments higher in industry data (2016 £) | 6,406,351.2 | |
| 5 | Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data (2016 £) | 2,960,716.0 | |
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Calculations based on the value of payments - relative differences

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| 9 | | | |
| 10 | Number of drug companies with relative difference <10% | 3 | 4.1% |
| 11 | Number of drug companies with relative difference <20% | 9 | 12.2% |
| 12 | Number of drug companies with relative difference <50% | 14 | 18.9% |
| 13 | Number of drug companies with relative difference <50% | | |
| 14 | Number of drug companies with relative difference = 100% | 24 | 32.4% |
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Recipients

Of the 425 recipients identified in industry data, 33 (7.8%) had matching payments numbers in both datasets, while 335 (78.8%) had a greater number in industry data (Table 3, web supplement 5). In relative terms, 225 (52.9%) recipients had payments reported only in industry data (the relative difference of 100%), while 81 (19.1%) had a relative difference lower than 50%.

Of 425 recipients, 416 (97.9%) had payments with a value greater than 0 in at least one dataset (web supplement 5). Of those, 356 (85.6%) had a higher value of payments in industry data, and 8 (1.9%) had matching payment values. In relative terms, 295 (70.9%) recipients had payments reported exclusively in industry data, and 73 (17.5%) recipients had a relative difference lower than 50%.

Overall, recipients with a high overall number and value of payments usually had high absolute differences (web supplement 5). Relative differences were lower for recipients with higher overall number and value of payments.

The shares of recipients with matching numbers and values of payments showed no improvement over time, but the shares of those with relative differences lower than 50% increased (from 13.7% to 17.3% and from 9.7% to 14.5%, respectively) (web supplement 6).

Table 3 – Recipients – absolute and relative differences in the number and value of payments

| | All years | % |
|---|-----------|-------|
| Calculations based on the number of payments - absolute differences | | |
| Number of patient organisations with at least one payment in at least one dataset - industry and patient organisation data | 425 | |
| Number of patient organisations with exact match in both datasets | 33 | 7.8% |
| Number of patient organisations with more payments in industry data | 335 | 78.8% |
| Number of patient organisations with more payments in patient organisation data | 57 | 13.4% |
| Highest absolute difference between patient organisation and industry data - number of payments higher in industry data | 199 | |
| Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data | 33 | |
| Calculations based on the number of payments - relative differences | | |
| Number of patient organisations with relative difference <10% | 35 | 8.2% |
| Number of patient organisations with relative difference <20% | 42 | 9.9% |
| Number of patient organisations with relative difference <50% | 81 | 19.1% |
| Number of patient organisations with relative difference = 100% | 225 | 52.9% |
| Calculations based on the value of payments - absolute differences | | |
| Number of patient organisations with at least one payment with value >£0 in at least one dataset | 416 | 100% |
| Number of patient organisations with exact match in both datasets | 8 | 1.9% |
| Number of patient organisations with higher payment value in industry data | 356 | 85.6% |
| Number of patient organisations with higher payment value in patient organisation data | 52 | 12.5% |

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| 5 | Highest absolute difference between patient organisation and industry data - number of payments higher in industry data (2016 £) | 6,718,576.6 | |
| 6 | Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data (2016 £) | 6,493,237.1 | |
| 7 | | | |

Calculations based on the value of payments - relative differences

| | | | |
|----|---|-----|-------|
| 10 | | | |
| 11 | Number of patient organisations with relative difference <10% | 21 | 5.0% |
| 12 | Number of patient organisations with relative difference <20% | 34 | 8.2% |
| 13 | Number of patient organisations with relative difference <50% | 73 | 17.5% |
| 14 | Number of patient organisations with relative difference <50% | | |
| 15 | Number of patient organisations with relative difference = 100% | 295 | 70.9% |
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Missing payments

After analysing the pattern of absolute and relative differences we now focus on donors and recipients with the relative difference of 100%, that is, those with payments reported only in either industry or patient organisation data.

Industry data

There were 24 donors, representing 38.1% of those in industry data, which seemed not to comply with the ABPI Code¹² as their payments were reported exclusively in patient organisation data over the entire period of observation (web supplement 7, 8, 9). The number and value of payments associated with these donors (in patient organisation data) were 128 and £1,610,321.1, equivalent to 3% of the number and value of payments in industry data. The annual shares of missing donors and their payments were considerably higher as some companies did not report payments only in some years. The annual shares of missing payments were decreasing over time.

Patient organisation data

There were 3 donors, constituting 3.6% of those in patient organisation data, whose payments were only reported in industry data (web supplement 10, 11, 12). The number and value of payments associated with these donors (in industry data) were 9 and £92,208.2, constituting 0.5% and 0.3% of the number and value of payments in patient organisation data. As with industry data, the annual shares of missing donors and their payments were higher as some donors were not reported in patient organisation data only in some years. The annual shares of missing payments were decreasing during the study period.

There were 225 recipients missing from patient organisation data, representing 112.5% of recipients in this dataset (web supplement 13, 14, 15). The number and value of missing payments were 1,472 and £14,023,475.41 (88.6% and 42.4% of the respective figures in patient organisation data). The yearly share of missing recipients and their payments increased, while the yearly share of missing payment values decreased.

Agreement between donor-recipient ties reported by industry and patient organisations

After describing the underreporting as a donor/recipient characteristic we now consider it by examining the distribution of ties – or connections – between donors and recipients in each dataset

There were 1101 ties between donors and recipients formed by at least one payment in industry data and 626 in patient organisation data (Table 4). In 428 instances both datasets agreed about the donors and recipients, representing 38.9% and 68.4% of ties in each dataset, respectively. Of these, in 87 (20.3%) instances both donors and recipients reported the same number of payments. The number of payments constituting those matching ties

1
2
3 was 162, equivalent to 3.8% and 9.8% of the total in industry and patient organisation data,
4 respectively.
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6
7 There were 1,088 ties involving payments with a value greater than zero in industry data and
8 326 in patient organisation data. In 34 instances, both datasets agreed about donors and
9 recipients (3.1% and 10.4% of ties in each dataset). Of these, in 20 instances (58.8%)
10 instances both sides provided matching payment values. The ties with matching values were
11 worth £325,108.4, representing 0.6% and 1.0.% of the value of payments in industry and
12 patient organisation data, respectively.
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15 The proportion of shared ties remained stable across time (web supplement 16).
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Table 4 – Shared ties in industry and patient organisation data

Ties calculated based on the number of payments

All years

| | |
|--|-------|
| Total number of ties reported in industry data involving at least one payment | 110 |
| Total number of ties reported in patient organisation data involving at least one payment | 62 |
| Number of shared ties (donors and recipients are the same in industry and patient organisation data) | 42 |
| Shared ties as a share of all ties in industry data | 38.9% |
| Shared ties as a share of all ties in patient organisation data | 68.4% |
| Number of ties involving the same number of payments | 87 |
| Number of ties involving the same number of payments as a share of shared ties | 20.5% |
| Number of payments forming ties with the equal number of payments in both datasets | 16 |
| Payments forming ties with the equal number of payments in both datasets as a share of all payments in industry data | 3.8% |
| Payments forming ties with the equal number of payments in both datasets as a share of all payments in patient organisation data | 9.8% |

Ties calculated based on the value of payments

| | |
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| Total number of ties reported in industry data involving at least one payment with value >£0 | 108 |
| Total number of ties reported in patient data involving at least one payment with value >£0 | 32 |
| Number of shared ties (donors and recipients are the same in industry and patient organisation data) | 34 |
| Shared ties as a share of all ties in industry data | 3.1% |
| Shared ties as a share of all ties in patient organisation data | 10.4% |
| Number of shared ties involving the same value of payments | 20 |
| Shared ties involving the same value of payments as a share of shared ties | 58.3% |

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| Value of payments in which donors and recipients provided the same value (2016 £) | 325,188.4 |
| Value of shared payments as a share of payments with values >£0 in industry data | 0.6% |
| Value of shared payments as a share of payments with values >£0 in patient organisation data | 1.0% |

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Overlap between recipient and donor lists in the two datasets

Having compared the distribution of ties in each dataset, we now consider ties as a characteristic of donors and recipients. Specifically, we analyse underreporting by comparing donor and recipient lists in each dataset against the other dataset.

Figure 1 Overlap between recipient and donor lists

Overlap between recipient lists and patient organisation data

Of 63 donors reporting at least one payment in the industry dataset, only 3 (4.8%) had all their recipients mentioning them as donors, the situation representing the full overlap between recipient lists and patient organisation data (Figure 1A). Conversely, the recipient lists of 6 (9.5%) donors had zero overlap with patient organisation data. The recipient lists of the remaining donors were situated between the two extremes, with 40 (63.5%) donors having less than 50% overlap, meaning that only half of the recipients were reflected in patient organisation data.

Considering the recipient lists calculated using the value of payments (62 donors reporting payment values greater than zero), the full and zero overlap occurred for 2 (3.2%) and 17 (27.0%) donors, respectively (Figure 1B). Overall, 56 (90.3%) donors had less than 50% overlap with patient organisation data.

Overlap between donors lists and industry data

Of the 200 recipients in patient organisation data, 102 (51.0%) had all donors mentioning them as recipients, which represented the full overlap between donor lists and industry data (Figure 1C). Contrastingly, the donor lists of 14 (7.4%) recipients had no overlap with industry data. Overall, 32 (16.0%) recipients had less than 50% overlap with industry data.

Based on the value of payments (121 recipients reporting payment values greater than zero), the full and zero overlap occurred for 71 (58.7%) and 12 (9.9%) recipients, respectively (Figure 1D). There were 18 (14.9%) donors with less than 50% overlap with industry data.

Over time, there was little improvement in the share of patient organisations reporting funding from drug companies listing them as recipients (web supplement 17 and 18). On the other hand, donors were reporting an increasing share of patient organisations mentioning their funding (web supplement 19 and 20).

Discussion

Principal findings

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3 Our study confirms that earlier concerns about the underreporting of payments in relation
4 to specific drug companies¹⁴ and charities^{33 34} were not isolated instances. It demonstrates
5 that neither the industry self-regulatory system for disclosure of payments to patient
6 organisations¹ nor a state-run system built for broader financial transparency purposes
7 succeeded in preventing a high extent of underreporting. Importantly, the underreporting
8 occurred despite the increasing media and research salience of the transparency of financial
9 relationships between the industry and patient organisations^{18 35 36 37}.

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13 Although some yearly variation might be expected given, for example, differences between
14 when a payment was made and when it was received or spent, the overall large and
15 seemingly increasing discrepancies between industry and patient organisation records are
16 concerning. The number and value of payments disclosed by drug companies were likely to
17 be higher because the ABPI Code has a formal definition of a payment and stipulates that
18 payment values should be recorded whenever possible.¹² Charity regulators lack similar
19 specific requirements.³⁸ Further, some patient organisations may redistribute money to
20 other collaborating entities and therefore they may report smaller amounts than donating
21 drug companies.³⁹ Nevertheless, any differences between donor and recipient records
22 should be minimised by the requirement for a written contract between the parties,
23 introduced by the ABPI Code, implying a shared understanding of how much is paid, to
24 whom, and how.¹²

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29 What also indicates underreporting is that few companies and patient organisations had
30 matching – or even broadly similar – records in the two datasets, with many having
31 differences exceeding hundreds of payments or worth millions of pounds. Both drug
32 companies and patient organisations had a larger number of payments in the other dataset,
33 but for both sides the value of payments was greater in industry data. The contrast between
34 the datasets was higher for patient organisations, with an overwhelming majority having a
35 greater number and value of payments reported in industry data. This pattern suggests
36 inadequacies of the existing governance of the reporting of corporate payments by the
37 charity regulators. It further corresponds with the results of a journalistic investigation into
38 the underreporting of payments by a major charity,^{33 34} prompting a rebuke from a charity
39 regulator.⁴⁰

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44 We also unearthed a number of unreported payments associated with companies missing
45 from either dataset. The underreporting of payments is further indicated by the fact that ties
46 – or donor-recipient connections – shared by both datasets were in minority. This was
47 particularly the case for ties involving matching payment numbers or values. The extent of
48 the overlap between donor and recipient lists reported in the two datasets was similarly
49 limited. Overall, this means that donors and recipients rarely disclosed payments reported
50 by the other side.

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54 As drug companies from our sample were signatories of the ABPI Code, missing payments
55 indicate that they either did not meet the obligation to disclose or met it but subsequently
56 removed their online disclosure reports. We could not find any evidence of specific
57 obligations for UK charities to name funders in their accounts.³⁸ Their absence is motivated
58 by concerns that “the loss of donor anonymity would result in a decrease in voluntary
59 income reported by charities. There were also concerns about the practical implications and
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3 about how much interest ‘general users’ of charity accounts would have in this disclosure.”⁴¹
4 Nevertheless, any unreported payments could be misleading for patient organisation
5 members, supporters, expert bodies relying on patient testimonies,²⁰ policymakers, and the
6 public.^{33 40} Unreported payments may sometimes indicate a culture characterised by
7 corporate manipulation of patient organisations.^{42 43} Indeed, an oft-used argument for
8 increasing transparency of payments not only to patient organisations but also medical
9 professionals and scientists is that “sunshine” mitigates against misbehaviour and undue
10 influence.⁴⁴
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14 A similarly high extent of underreporting has been identified in other countries and other
15 recipients of industry payments. For example, a study of the underreporting of conflicts of
16 interest (COIs) in Danish clinical practice guidelines in 2012 identified that only one of the 45
17 surveyed guidelines disclosed author COIs.²² A related Australian study found that about one
18 in four guideline writers may have potentially relevant undisclosed ties to pharmaceutical
19 companies.²³ Similarly, US studies have repeatedly found significant discrepancies between
20 self-reported COIs by authors of scientific publications and the mandatory payment reports
21 in the Open Payments database,^{25 26 28} for example, a study of oncologist authors of clinical
22 trial publications in high-impact journals established that one-third failed to completely
23 disclose payments from the study sponsor.²⁶
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27 Strengths and limitations

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30 This is the first study examining the underreporting of payments to patient organisations
31 using large samples of donors and recipients over a period of time. It systematically
32 compares the underreporting by the two sides using five complementary measures. These
33 measures account for the varying nature of different types of payment data and therefore
34 can be replicated in other countries.
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38 Our study has several important limitations. First, while Disclosure UK covers a vast majority
39 of the UK pharmaceutical industry,¹³ our sample was not exhaustive, as demonstrated by
40 additional companies found in patient organisation accounts. Second, excluding companies
41 outside of our sample is likely to have underestimated the underreporting. However, several
42 further rounds of data scrapping on industry and charity regulators’ websites would be
43 necessary to reach data saturation. Third, we identified patient organisations using drug
44 company disclosure reports, but a sampling strategy starting from patient organisations
45 could have led to different results. Fourth, patient organisations registered with charity
46 regulators are not required to submit annual accounts if their yearly income is lower than
47 £25,000; therefore we might have excluded, entirely or in specific years, some of the patient
48 organisations identified as recipients of industry funding, if their yearly incomes were below
49 that threshold. Fifth, some patient organisations were excluded due to the conversion of
50 financial years into calendar years, which might have increased discrepancies with drug
51 company disclosure reports. Sixth, some companies might have reported payments made in
52 2016 in subsequent years, but the extent of delayed reporting is likely to have been
53 minimal.¹ We did not identify instances of delayed reporting in patient organisation annual
54 accounts. Seventh, we only considered annual accounts submitted to charity regulators,
55 while funders might have also (or instead) been disclosed on the charity’s website. However,
56 website disclosures would be likely to undergo frequent changes, and have often been
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3 found to lack transparency.^{15 16 17 18 19} Eight, evaluating the extent of underreporting
4 precisely is impossible because no definitive list of payments exists; consequently, there
5 could be payments undisclosed by both sides. Finally, considering payment descriptions
6 could reveal further discrepancies, including different payment goals reported by donors and
7 recipients; it could also identify payments made via third parties (e.g. public relations or
8 consultancy companies⁴⁰) or benefitting patient organisations indirectly.¹⁴
9
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11 Conclusions and policy implications

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14 Although the full scale of underreporting of industry payments to patient organisations
15 remains unknown, it concerns both donors and recipients, and involves a considerable
16 number and value of payments. Our findings put a question mark over the key claim that –
17 at least in their current form – publicly available payment disclosures effectively address
18 concerns about COIs resulting from industry payments.
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21 Against this background, we provide evidence for developing easily achievable
22 improvements in the reporting of payments by both donors and recipients. Drug companies
23 should improve data presentation using recommendations already formulated,¹⁴ especially
24 standardisation of reporting and elimination of payments with no assigned values.
25 Companies should store data for at least as long as is required by the Charity Commission,
26 that is five years. Given the shortcomings of the industry self-regulatory system, charity
27 regulators should introduce tailored solutions related to reporting corporate funding in
28 annual accounts, including a standardised template comprising a short payment description
29 (including payment form and goal), its value, and donor name. Patient organisation websites
30 should report this information separately or include clear signposting to the annual
31 accounts. However, only a single state-run permanent database integrating payments
32 reported by drug companies and patient organisations could eliminate underreporting.
33 Finally, any payment disclosure system must have built-in checks to ensure comprehensive
34 disclosure.
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Figure 1

The bars in Figures 1A-1B show the number of donors with varying level of overlap between their recipient lists and patient organisation data based on the number (Figure 1A) and value (Figure 1B) of payments. For example, based on the number of payments there were 13 companies with 20-29.9% recipients also being reported in patient organisation data (Figure 1A).

The bars in Figures 1C-1D show the number of recipients with varying level of overlap between their donor lists and industry data based on the number (Figure 1C) and value (Figure 1D) of payments. For example, based on the number of payments there were 24 recipients with 50-59.9% of donors also being reported in industry data.

Contributors

PO conceived and designed the study, managed, analysed and interpreted the data, as well as drafted the article MC analysed the data and drafted the article. ER collected and managed the data, and drafted the article. SM designed the study, contributed to interpretation, drafted the article

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Details of the role of study sponsors

The funding body has played no part in the design or conduct of this study

Statement of independence of researchers from funders

All researchers working on this study are independent from the funding body.

Competing interests

We have read and understood the BMJ Group policy on declaration of interests and declare the following interests:

Shai Mulinari and Piotr Ozieranski's work on the study reported in this paper was supported by the grant "What can be learnt from the new pharmaceutical industry payment disclosures?" awarded by the Swedish Research Council for Health, Working Life and Welfare (FORTE #2016-00875). Emily Rickard's work was funded through the above grant. Marcell Csanadi did not receive funding for this work. We have no other competing interests to declare.

Patient consent

None required.

Ethical approval

No ethical approval was needed.

Data sharing

The authors of this study agree to share data underpinning this study in the form of web supplements. The raw data poses no risk to anonymity of individuals as it draws on publicly available reports concerning financial transfers between organisations.

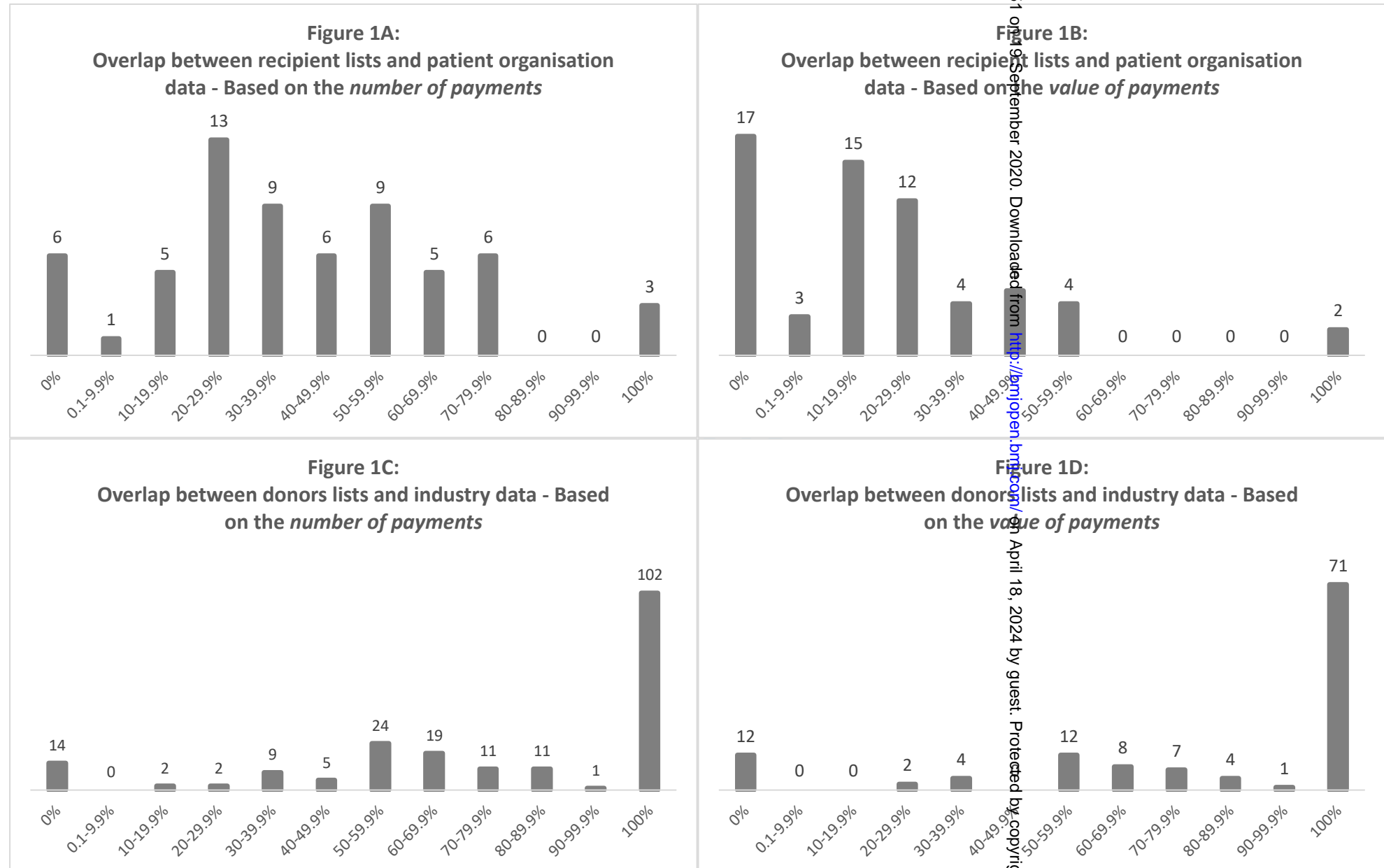
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Transparency declaration

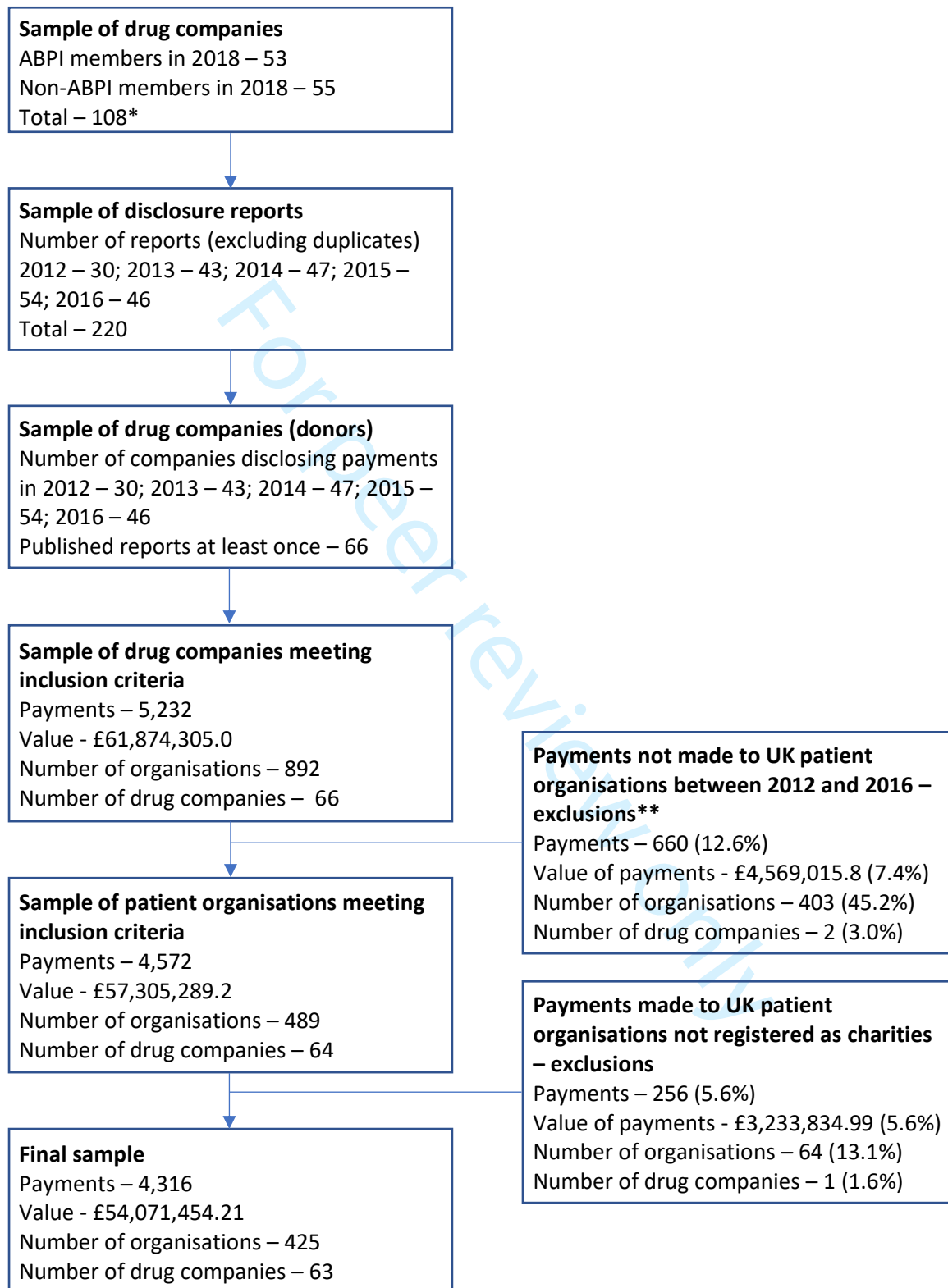
The guarantor (Piotr Ozieranski) affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Figure 1. Overlap between recipient and donor lists



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Web supplement 1 – Research process: pharmaceutical industry data



*Complete lists of companies provided in Table 1

**Detailed breakdown provided in Table 2

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

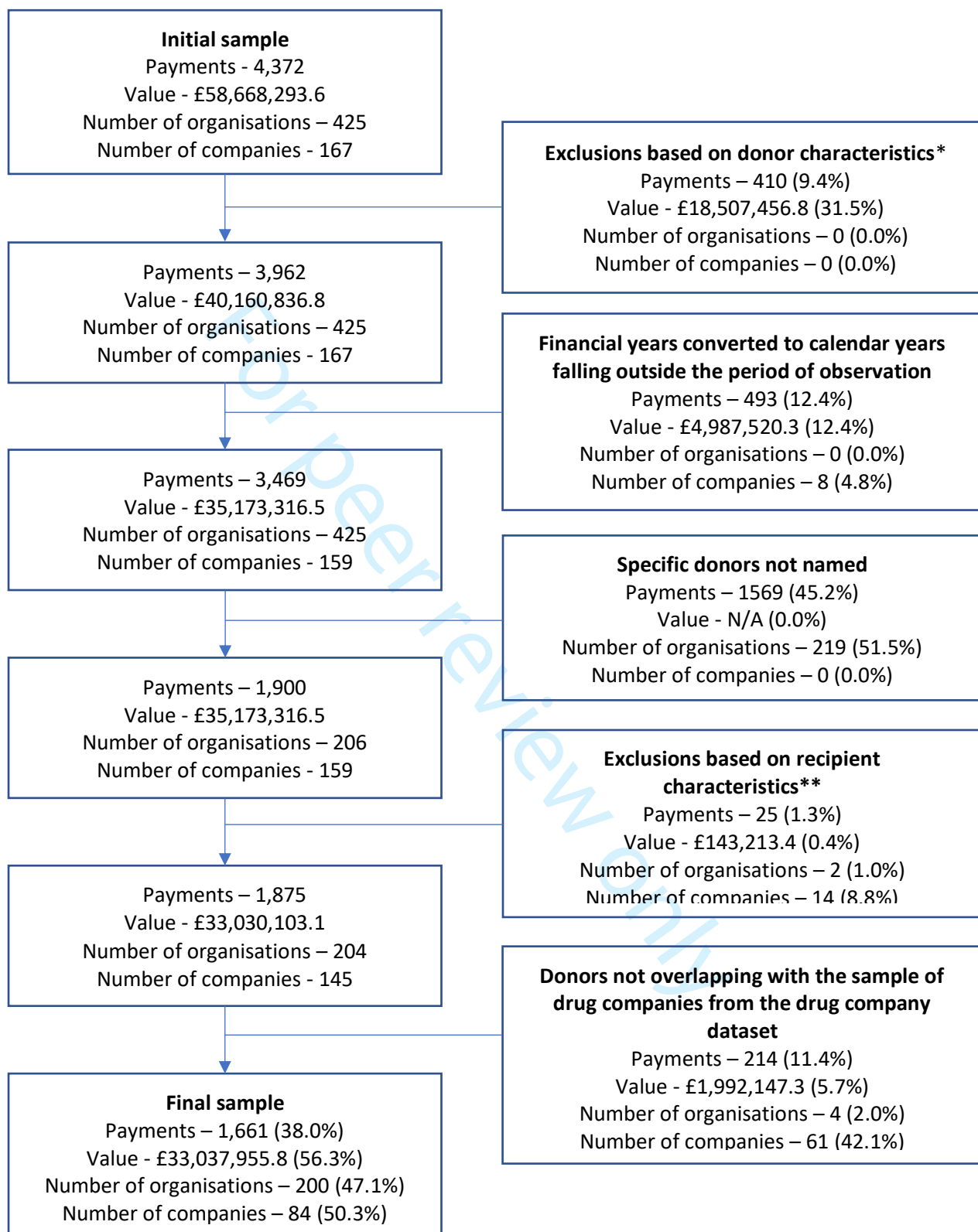
| ABPI member in 2018 – n=53 | Non-ABPI member in 2018 – n=55 |
|----------------------------|--------------------------------|
| A. Menarini | Accretio |
| Abbvie | Actavis |
| Actelion | Aegerion |
| Alexion | Aguettant |
| Alimera Sciences | Alcon |
| ALK-Abelo | AMCo |
| Allergan | ApoPharma |
| 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 UK organisation | 54 (8.2) | 716,044.0 (15.7) | 30 (7.4) |
| <i>Excluded UK organisations</i> | | | |
| 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) |

Web supplement 2 Research process: patient organisation data



*More detailed breakdown in Table 3

**More detailed breakdown in Table 4

Table 3. Exclusions based on donor characteristics – detailed breakdown

| Reason for exclusion | Number of Payments excluded | Value of payments excluded (£) |
|---|-----------------------------|--------------------------------|
| <i>Exclusions unique to patient organisation dataset</i> | | |
| Regional branch (same charity number as national branch) | 229 | 13,213,514.2 |
| Subsumed under a larger organisation (same charity number as larger organisation) | 125 | 291,862.9 |
| Years before merger | 14 | 1,515.0 |
| Years after merger | 9 | - |
| <i>Exclusions resulting from exclusions in drug company dataset</i> | | |
| Third sector - healthcare provider | 6 | - |
| Third sector - professional organisation | 6 | - |
| Third sector - not focusing directly on health | 15 | 5,000,564.8 |
| Not a charity | 6 | - |
| Total | 410 | 18,507,456.8 |

Table 4. Exclusions based on recipient characteristics – detailed breakdown

| | Number of Payments excluded | Value of payments excluded (£) | Number of drug companies excluded | Number of patient organisations excluded |
|------------------------------|-----------------------------|--------------------------------|-----------------------------------|--|
| More than one organisation | 8 | 58,485.5 | 7 | 0 |
| Not a pharmaceutical company | 17 | 84,727.8 | 7 | 2 |
| Total | 25 | 143,213.4 | 14 | 2 |

Web Supplement 3. Donors - Absolute and relative differences in the number and value of payments

NUMBER OF PAYMENTS

Number of payments - industry data

Number of payments - patient organisation data

Number of drug companies with at least one payment - industry data

Number of drug companies with at least one payment - patient organisation data

NUMBER OF PAYMENTS - THRESHOLDS

Threshold 0: Number of drug companies with at least 1 one payment in at least one dataset (1 if cond

Threshold 1: Number of drug companies with more than 1 one payment in at least one dataset (1 if co

Threshold 2: Number of drug companies with more than 10 payments in at least one dataset (1 if con

Threshold 3: Number of drug companies with more than 100 payments in at least one dataset (1 if co

NUMBER OF PAYMENTS - ABSOLUTE DIFFERENCES

Number of payments - threshold 0

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Number of payments - threshold 1

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Number of payments - threshold 2

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Number of payments - threshold 3

1
2 Number of drug companies with exact match in both datasets
3 Number of drug companies with more payments in industry data
4 Number of drug companies with more payments in patient organisation data
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7

8 Highest absolute difference between patient organisation and industry data - number of payments hi
9 Highest absolute difference between patient organisation and industry data - number of payments hi
10
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NUMBER OF PAYMENTS - RELATIVE DIFFERENCES

12
13
14
15 Relative difference <10%
16 Relative difference <20%
17 Relative difference <50%
18 Relative difference = 100%
19
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21

Number of payments - threshold 1

22
23 Relative difference <10%
24 Relative difference <20%
25 Relative difference <50%
26 Relative difference = 100%
27
28
29

Number of payments - threshold 2

30
31 Relative difference <10%
32 Relative difference <20%
33 Relative difference <50%
34 Relative difference = 100%
35
36
37

Number of payments - threshold 3

38
39 Relative difference <10%
40 Relative difference <20%
41 Relative difference <50%
42 Relative difference = 100%
43
44
45

VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES

46
47
48 Value of payments - industry data (2016 £)
49 Value of payments - patient organisation data (2016 £)
50 Number of payments with value >£0 - industry data
51 Number of payments with value >£0 - patient organisation data
52 Number of drug companies with at least one payment with the value >£0 - industry data
53 Number of drug companies with at least one payment with the value >£0 - patient organisation data
54
55
56

VALUE OF PAYMENTS - THRESHOLDS

57
58
59
60 Threshold 1: Number of drug companies with at least one payment with value >£0 in at least one data
Threshold 2: Number of drug companies with payments with the value of more than £10,000 in at least one data

1
2 Threshold 3: Number of drug companies with payments with the value of more than £100,000 in at le
3

4
5 **VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES**

6 **Number of payments - threshold 1**

7 Number of drug companies with exact match in both datasets

8 Number of drug companies with higher payment value in industry data

9 Number of drug companies with higher payment value in patient organisation data
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13 Highest absolute difference between patient organisation and industry data - number of payments hi

14 Highest absolute difference between patient organisation and industry data - number of payments hi
15
16

17
18 **Number of payments - threshold 2**

19 Number of drug companies with exact match in both datasets

20 Number of drug companies with higher payment value in industry data

21 Number of drug companies with higher payment value in patient organisation data
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25 Highest absolute difference between patient organisation and industry data - number of payments hi

26 Highest absolute difference between patient organisation and industry data - number of payments hi
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29
30 **Number of payments - threshold 3**

31 Number of drug companies with exact match in both datasets

32 Number of drug companies with higher payment value in industry data

33 Number of drug companies with higher payment value in patient organisation data
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37 Highest absolute difference between patient organisation and industry data - number of payments hi

38 Highest absolute difference between patient organisation and industry data - number of payments hi
39
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41
42 **VALUE OF PAYMENTS - RELATIVE DIFFERENCES**

43
44 Relative difference <10%

45 Relative difference <20%

46 Relative difference <50%

47 Relative difference = 100%
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50
51 **Number of payments - threshold 1**

52 Relative difference <10%

53 Relative difference <20%

54 Relative difference <50%

55 Relative difference = 100%
56
57

58
59 **Number of payments - threshold 2**

60 Relative difference <10%

Relative difference <20%

- 1
- 2 Relative difference <50%
- 3 Relative difference = 100%
- 4
- 5

Number of payments - threshold 3

- 7 Relative difference <10%
- 8 Relative difference <20%
- 9
- 10 Relative difference <50%
- 11 Relative difference = 100%
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| | | | A. Menarini | Abbvie | Actavis | Actelion |
|--|--------|--|-------------|--------|---------|----------|
| Total | | | 1 | 1 | 0 | 1 |
| 4316 | | | 3 | 281 | 5 | 38 |
| 1661 | | | 0 | 84 | 5 | 23 |
| 63 | | | 1 | 1 | 1 | 1 |
| 84 | | | 0 | 1 | 1 | 1 |
| Number of drug cc% of all drug companies with at least one payment in at least one dataset | | | | | | |
| 87 | 100.0% | | 1 | 1 | 1 | 1 |
| 80 | 92.0% | | 1 | 1 | 1 | 1 |
| 47 | 54.0% | | | 1 | | 1 |
| 10 | 11.5% | | | 1 | | |
| Number of drug cc% of all drug companies at a given threshold | | | | | | |
| 3 | 3.4% | | | | 1 | |
| 49 | 56.3% | | 1 | 1 | | 1 |
| 35 | 40.2% | | | | | |
| Number of payments | | | | | | |
| 757 | | | 3 | 197 | | 15 |
| 53 | | | | | | |
| Number of drug cc% of all drug companies at a given threshold | | | | | | |
| 3 | 3.8% | | | | 1 | |
| 49 | 61.3% | | 1 | 1 | | 1 |
| 28 | 35.0% | | | | | |
| Number of payments | | | | | | |
| 757 | | | 3 | 197 | | 15 |
| 53 | | | | | | |
| Number of drug cc% of all drug companies at a given threshold | | | | | | |
| 1 | 2.1% | | | | | |
| 36 | 76.6% | | | 1 | | 1 |
| 10 | 21.3% | | | | | |
| Number of payments | | | | | | |
| 757 | | | | 197 | | 15 |
| 53 | | | | | | |
| Number of drug cc% of all drug companies at a given threshold | | | | | | |

| | | | | | | |
|----|---|-----|----------|-------------|----------|-----------|
| 1 | | | | | | |
| 2 | | 0 | 0.0% | | | |
| 3 | | 10 | 100.0% | 1 | | |
| 4 | | 0 | 0.0% | | | |
| 5 | | | | | | |
| 6 | | | | | | |
| 7 | Number of payments | | | | | |
| 8 | | 757 | | 197 | | |
| 9 | | 0 | | | | |
| 10 | | | | | | |
| 11 | | | | | | |
| 12 | | | | | | |
| 13 | | | | | | |
| 14 | Number of drug cc% of all drug companies | | | | | |
| 15 | | 5 | 5.7% | | 0.0% | |
| 16 | | 9 | 10.3% | | 0.0% | |
| 17 | | 21 | 24.1% | | 0.0% | 39.5% |
| 18 | | 27 | 31.0% | 100.0% | | |
| 19 | | | | | | |
| 20 | | | | | | |
| 21 | | | | | | |
| 22 | Number of drug cc% of all companies at a given threshold | | | | | |
| 23 | | 5 | 6.3% | | 0.0% | |
| 24 | | 9 | 11.3% | | 0.0% | |
| 25 | | 21 | 26.3% | | 0.0% | 39.5% |
| 26 | | 20 | 25.0% | 100.0% | | |
| 27 | | | | | | |
| 28 | | | | | | |
| 29 | | | | | | |
| 30 | Number of drug cc% of all companies at a given threshold | | | | | |
| 31 | | 3 | 6.4% | | | |
| 32 | | 5 | 10.6% | | | |
| 33 | | 15 | 31.9% | | | 39.5% |
| 34 | | 2 | 4.3% | | | |
| 35 | | | | | | |
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| 38 | Number of drug cc% of all companies at a given threshold | | | | | |
| 39 | | 0 | 0.0% | | | |
| 40 | | 0 | 0.0% | | | |
| 41 | | 1 | 10.0% | | | |
| 42 | | 0 | 0.0% | | | |
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| 47 | Total | | | | | |
| 48 | £54,071,454.2 | | 33,907.5 | 3,584,604.6 | 49,000.0 | 364,970.8 |
| 49 | £33,037,955.8 | | - | 1,412,340.9 | 49,240.0 | 217,382.1 |
| 50 | | | | | | |
| 51 | 4235 | | 3 | 281 | 5 | 38 |
| 52 | 772 | | 0 | 40 | 2 | 16 |
| 53 | 62 | | 1 | 1 | 1 | 1 |
| 54 | 62 | | 0 | 1 | 1 | 1 |
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| 59 | Number of drug cc% of all drug companies with at least one payment with the value of at least | | | | | |
| 60 | | 74 | 85.1% | 1 | 1 | 1 |
| | | 45 | 51.7% | 1 | 1 | 1 |

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|---|-------------|-------|--------|---------|------|--------|
| | 17 | 19.5% | | 1 | | |
| Number of drug cc% of all drug companies at a given threshold | | | | | | |
| | 0 | 0.0% | | | | |
| | 48 | 64.9% | 1 | 1 | | 1 |
| | 26 | 35.1% | | | 1 | |
| Vallue of payments | | | | | | |
| | 6,406,351.1 | | 33908 | 2172264 | | 147589 |
| | 2,960,716.0 | | | | 240 | |
| Number of drug cc% of all drug companies at a given threshold | | | | | | |
| | 0 | 0.0% | | | | |
| | 32 | 71.1% | | 1 | | 1 |
| | 13 | 28.9% | | | | |
| Vallue of payments | | | | | | |
| | 6,406,351.1 | | | 2172264 | | 147589 |
| | 2,960,716.0 | | | | | |
| Number of drug cc% of all drug companies at a given threshold | | | | | | |
| | 0 | 0.0% | | | | |
| | 13 | 76.5% | | 1 | | |
| | 4 | 23.5% | | | | |
| Vallue of payments | | | | | | |
| | 6,406,351.1 | | | 0 | | |
| | 2,960,716.0 | | | 2172264 | | |
| Number of drug cc% of all drug companies with at least one payment with value >£0 in at least | | | | | | |
| | 3 | 4.1% | | | 0.5% | |
| | 9 | 12.2% | | | 0.5% | |
| | 14 | 18.9% | | | 0.5% | 40.4% |
| | 24 | 32.4% | 100.0% | | | |
| Number of drug cc% of all drug companies at a given threshold | | | | | | |
| | 3 | 4.1% | | | 0.5% | |
| | 9 | 12.2% | | | 0.5% | |
| | 14 | 18.9% | | | 0.5% | 40.4% |
| | 24 | 32.4% | 100.0% | | | |
| Number of drug cc% of all drug companies at a given threshold | | | | | | |
| | 1 | 2.2% | | | | |
| | 5 | 11.1% | | | | |

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| | |
|---|-------|
| 9 | 20.0% |
| 4 | 8.9% |
| Number of drug cc% of all drug companies at a given threshold | |
| 0 | 0.0% |
| 2 | 11.8% |
| 2 | 11.8% |
| 1 | 5.9% |

40.4%

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| | Aegerion | Alcon | Alexion | ALK-Abello | Allergan | Alliance | Almirall |
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| 5 | 0 | 0 | 1 | 1 | 1 | 1 | 1 |
| 6 | | | | | | | |
| 7 | 5 | 1 | 5 | 0 | 25 | 0 | 9 |
| 8 | 4 | 9 | 17 | 2 | 26 | 1 | 2 |
| 9 | | | | | | | |
| 10 | 1 | 1 | 1 | 0 | 1 | 0 | 1 |
| 11 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
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| 16 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| 17 | 1 | 1 | 1 | 1 | 1 | | 1 |
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| - | 83,733.8 | 70,583.4 | - | 148,240.9 | - | - |
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| | Amdipharm | Amgen | ApoPharma | Astellas | AstraZeneca | ausch and Lom |
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For peer review only

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|----------|-----------|----------|-------------|-----------|----------|
| - | 699,274.6 | - | 2,783,709.6 | 725,306.3 | - |
| 34,433.3 | 324,720.9 | 76,194.8 | 80,417.4 | 42,450.6 | 22,627.3 |
| 0 | 82 | 0 | 74 | 53 | 0 |
| 3 | 22 | 5 | 4 | 6 | 2 |
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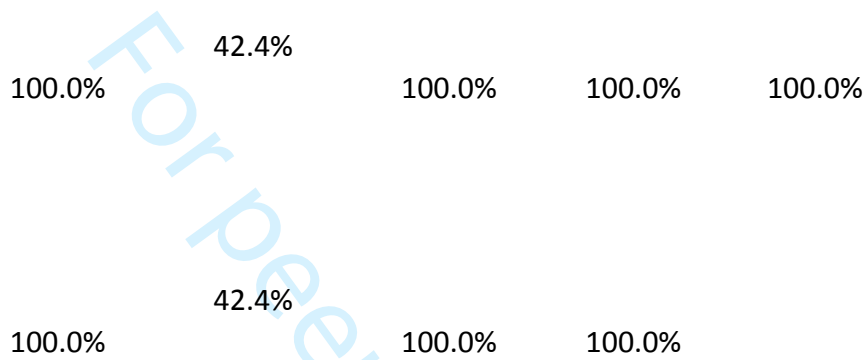
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| 49 | 32,002.9 | 84,069.3 | - | 2,828,703.7 |
| 51 | 7 | 84 | 0 | 3 |
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Web Supplement 4. Donors - Absolute and relative differences in the number and value of payments**NUMBER OF PAYMENTS - ABSOLUTE DIFFERENCES****Threshold 0: At least 1 one payment in at least one dataset**

Total

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher

Highest absolute difference between patient organisation and industry data - number of payments higher

Threshold 1: More than 1 one payment in at least one dataset

Total

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher

Highest absolute difference between patient organisation and industry data - number of payments higher

Threshold 2: More than 10 payments in at least one dataset

Total

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher

Highest absolute difference between patient organisation and industry data - number of payments higher

Threshold 3: More than 100 payments in at least one dataset

Total

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher

Highest absolute difference between patient organisation and industry data - number of payments higher

NUMBER OF PAYMENTS - RELATIVE DIFFERENCES**Threshold 0: At least 1 one payment in at least one dataset**

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2 Total
3 Relative difference <10%
4 Relative difference <20%
5 Relative difference <50%
6 Relative difference = 100%

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10 **Threshold 1: More than 1 one payment in at least one datase**

11 Total
12 Relative difference <10%
13 Relative difference <20%
14 Relative difference <50%
15 Relative difference = 100%

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19 **Threshold 2: More than 10 payments in at least one dataset**

20 Total
21 Relative difference <10%
22 Relative difference <20%
23 Relative difference <50%
24 Relative difference = 100%

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28 **Threshold 3: More than 100 payments in at least one dataset**

29 Total
30 Relative difference <10%
31 Relative difference <20%
32 Relative difference <50%
33 Relative difference = 100%

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37 **VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES**

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40 **Threshold 1: At least one payment with value >£0 in at least one dataset**

41 Total
42 Number of drug companies with exact match in both datasets
43 Number of drug companies with higher payment value in industry data
44 Number of drug companies with higher payment value in patient organisation data

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49 Highest absolute difference between patient organisation and industry data - number of payments hi
50 Highest absolute difference between patient organisation and industry data - number of payments hi

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53 **Threshold 2: Payments with the value of more than £10,000 in at least one dataset**

54 Total
55 Number of drug companies with exact match in both datasets
56 Number of drug companies with higher payment value in industry data
57 Number of drug companies with higher payment value in patient organisation data

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2 Highest absolute difference between patient organisation and industry data - number of payments hi
3 Highest absolute difference between patient organisation and industry data - number of payments hi
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6 **Threshold 3: Payments with the value of more than £100,000 in at least one dataset**

7 Total

8 Number of drug companies with exact match in both datasets

9 Number of drug companies with higher payment value in industry data

10 Number of drug companies with higher payment value in patient organisation data
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15 Highest absolute difference between patient organisation and industry data - number of payments hi

16 Highest absolute difference between patient organisation and industry data - number of payments hi
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19 **VALUE OF PAYMENTS- RELATIVE DIFFERENCES**
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21 **Threshold 1: At least one payment with value >£0 in at least one dataset**

22 Total

23 Relative difference <10%

24 Relative difference <20%

25 Relative difference <50%

26 Relative difference = 100%
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31 **Threshold 2: Payments with the value of at least £10,000 in at least one dataset**

32 Total

33 Relative difference <10%

34 Relative difference <20%

35 Relative difference <50%

36 Relative difference = 100%
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40 **Threshold 3: Payments with the value of at least 100,000 in at least one dataset**

41 Total

42 Relative difference <10%

43 Relative difference <20%

44 Relative difference <50%

45 Relative difference = 100%
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| Number of drug cc% of all drug c 0 | Number of drug% of all drug c 0 | Number of dru% of all drug c 0 | Number of dru% of all drug c 0 | Number of dru% of all drug c 0 | |
| 87 | 100.0% | 61 | 100.0% | 68 | 100.0% |
| 3 | 3.4% | 1 | 1.6% | 7 | 10.3% |
| 49 | 56.3% | 28 | 45.9% | 28 | 41.2% |
| 35 | 40.2% | 32 | 52.5% | 33 | 48.5% |
| Number of payments | Number of payments | Number of payments | Number of payments | Number of payments | |
| 757 | 216 | 135 | 135 | 135 | |
| 53 | 18 | 16 | 16 | 16 | |
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| 80 | 100.0% | 46 | 100.0% | 55 | 100.0% |
| 3 | 3.8% | 1 | 2.2% | 3 | 5.5% |
| 49 | 61.3% | 28 | 60.9% | 27 | 49.1% |
| 28 | 35.0% | 17 | 37.0% | 25 | 45.5% |
| Number of payments | Number of payments | Number of payments | Number of payments | Number of payments | |
| 757 | 216 | 135 | 135 | 135 | |
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| 47 | 100.0% | 16 | 100.0% | 17 | 100.0% |
| 1 | 2.1% | 0 | 0.0% | 0 | 0.0% |
| 36 | 76.6% | 13 | 81.3% | 14 | 82.4% |
| 10 | 21.3% | 3 | 18.8% | 3 | 17.6% |
| Number of payments | Number of payments | Number of payments | Number of payments | Number of payments | |
| 757 | 216 | 135 | 135 | 135 | |
| 53 | 18 | 16 | 16 | 16 | |
| Number of drug cc% of all drug c 0 | Number of drug% of all drug c 0 | Number of dru% of all drug c 0 | Number of dru% of all drug c 0 | Number of dru% of all drug c 0 | |
| 10 | 100.0% | 1 | 100.0% | 1 | 100.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 10 | 100.0% | 1 | 100.0% | 1 | 100.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| Number of payments | Number of payments | Number of payments | Number of payments | Number of payments | |
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|---|-------------|--------|-------------------|--------------|----|-------------------|------------|
| | 87 | 100.0% | 61 | 100.0% | 68 | 100.0% | |
| | 5 | 5.7% | 1 | 1.6% | 7 | 10.3% | |
| | 9 | 10.3% | 2 | 3.3% | 7 | 10.3% | |
| | 21 | 24.1% | 7 | 11.5% | 10 | 14.7% | |
| | 27 | 31.0% | 36 | 59.0% | 33 | 48.5% | |
| Number of drug cc% of all drug c 0 Number of drug% of all drug c 0 Number of dru% of all drug c 0 | | | | | | | |
| | 80 | 100.0% | 46 | 100.0% | 55 | 100.0% | |
| | 5 | 6.3% | 1 | 2.2% | 3 | 5.5% | |
| | 9 | 11.3% | 2 | 4.3% | 3 | 5.5% | |
| | 21 | 26.3% | 7 | 15.2% | 6 | 10.9% | |
| | 20 | 25.0% | 21 | 45.7% | 24 | 43.6% | |
| Number of drug cc% of all drug c 0 Number of drug% of all drug c 0 Number of dru% of all drug c 0 | | | | | | | |
| | 47 | 100.0% | 16 | 100.0% | 17 | 100.0% | |
| | 3 | 6.4% | 0 | 0.0% | 0 | 0.0% | |
| | 5 | 10.6% | 0 | 0.0% | 0 | 0.0% | |
| | 15 | 31.9% | 1 | 6.3% | 0 | 0.0% | |
| | 2 | 4.3% | 3 | 18.8% | 3 | 17.6% | |
| Number of drug cc% of all drug c 0 Number of drug% of all drug c 0 Number of dru% of all drug c 0 | | | | | | | |
| | 10 | 100.0% | 1 | 100.0% | 1 | 100.0% | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | |
| | 1 | 10.0% | 0 | 0.0% | 0 | 0.0% | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | |
| Number of drug cc% of all drug c 0 Number of drug% of all drug c 0 Number of dru% of all drug c 0 | | | | | | | |
| | 74 | 100.0% | 52 | 100.0% | 56 | 100.0% | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | |
| | 48 | 64.9% | 26 | 50.0% | 35 | 62.5% | |
| | 26 | 35.1% | 26 | 50.0% | 21 | 37.5% | |
| Value of payments | | | Value of payments | | | Value of payments | |
| | 6,406,351.2 | | | 1,576,293.48 | | | 666,171.11 |
| | 2,960,716.0 | | | 501,114.66 | | | 851,009.34 |
| Number of drug cc% of all drug c 0 Number of drug% of all drug c 0 Number of dru% of all drug c 0 | | | | | | | |
| | 45 | 100.0% | 20 | 100.0% | 24 | 100.0% | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | |
| | 32 | 71.1% | 13 | 65.0% | 14 | 58.3% | |
| | 13 | 28.9% | 7 | 35.0% | 10 | 41.7% | |
| Value of payments | | | Value of payments | | | Value of payments | |

| | | | | | | |
|----|------------------------------------|--------|---------------------------------|--------|--------------------------------|--------|
| 1 | | | | | | |
| 2 | 6,406,351.2 | | 1,576,293.5 | | 666,171.1 | |
| 3 | 2,960,716.0 | | 501,114.7 | | 851,009.3 | |
| 4 | | | | | | |
| 5 | | | | | | |
| 6 | Number of drug cc% of all drug c 0 | | Number of drug% of all drug c 0 | | Number of dru% of all drug c 0 | |
| 7 | 17 | 100.0% | 2 | 100.0% | 1 | 100.0% |
| 8 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 9 | | | | | | |
| 10 | 13 | 76.5% | 2 | 100.0% | 1 | 100.0% |
| 11 | 4 | 23.5% | 0 | 0.0% | 0 | 0.0% |
| 12 | | | | | | |
| 13 | | | | | | |
| 14 | Value of payments | | Value of payments | | Value of payments | |
| 15 | 6,406,351.2 | | 1,576,293.5 | | 604,556.0 | |
| 16 | 2,960,716.0 | | - | | - | |
| 17 | | | | | | |
| 18 | | | | | | |
| 19 | | | | | | |
| 20 | | | | | | |
| 21 | | | | | | |
| 22 | Number of drug cc% of all drug c 0 | | Number of drug% of all drug c 0 | | Number of dru% of all drug c 0 | |
| 23 | 74 | 100.0% | 52 | 100.0% | 56 | 100.0% |
| 24 | 3 | 4.1% | 1 | 1.9% | 0 | 0.0% |
| 25 | | | | | | |
| 26 | 9 | 12.2% | 1 | 1.9% | 4 | 7.1% |
| 27 | 14 | 18.9% | 4 | 7.7% | 7 | 12.5% |
| 28 | 24 | 32.4% | 32 | 61.5% | 30 | 53.6% |
| 29 | | | | | | |
| 30 | | | | | | |
| 31 | Number of drug cc% of all drug c 0 | | Number of drug% of all drug c 0 | | Number of dru% of all drug c 0 | |
| 32 | 45 | 100.0% | 20 | 100.0% | 24 | 100.0% |
| 33 | 1 | 2.2% | 0 | 0.0% | 0 | 0.0% |
| 34 | | | | | | |
| 35 | 5 | 11.1% | 0 | 0.0% | 1 | 4.2% |
| 36 | 9 | 20.0% | 1 | 5.0% | 3 | 12.5% |
| 37 | 4 | 8.9% | 8 | 40.0% | 9 | 37.5% |
| 38 | | | | | | |
| 39 | | | | | | |
| 40 | Number of drug cc% of all drug c 0 | | Number of drug% of all drug c 0 | | Number of dru% of all drug c 0 | |
| 41 | 17 | 100.0% | 2 | 100.0% | 1 | 100.0% |
| 42 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 43 | | | | | | |
| 44 | 2 | 11.8% | 0 | 0.0% | 0 | 0.0% |
| 45 | 2 | 11.8% | 0 | 0.0% | 1 | 100.0% |
| 46 | 1 | 5.9% | 0 | 0.0% | 0 | 0.0% |
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2015

2016

| Number of drug % of all drug c | | Number of drug % of all drug c | | Number of drug % of all drug c | |
|--------------------------------|--------|--------------------------------|--------|--------------------------------|--------|
| 72 | 100.0% | 74 | 100.0% | 69 | 100.0% |
| 4 | 5.6% | 7 | 9.5% | 4 | 5.8% |
| 38 | 52.8% | 42 | 56.8% | 39 | 56.5% |
| 30 | 41.7% | 25 | 33.8% | 26 | 37.7% |

| Number of payments | | Number of payments | | Number of payments | |
|--------------------|--|--------------------|--|--------------------|--|
| 108 | | 125 | | 173 | |
| 13 | | 13 | | 12 | |

| Number of drug % of all drug c | | Number of drug % of all drug c | | Number of drug % of all drug c | |
|--------------------------------|--------|--------------------------------|--------|--------------------------------|--------|
| 55 | 100.0% | 57 | 100.0% | 50 | 100.0% |
| 1 | 1.8% | 5 | 8.8% | 3 | 6.0% |
| 36 | 65.5% | 42 | 73.7% | 38 | 76.0% |
| 18 | 32.7% | 10 | 17.5% | 9 | 18.0% |

| Number of payments | | Number of payments | | Number of payments | |
|--------------------|--|--------------------|--|--------------------|--|
| 108 | | 125 | | 173 | |
| 13 | | 13 | | 12 | |

| Number of drug % of all drug c | | Number of drug % of all drug c | | Number of drug % of all drug c | |
|--------------------------------|--------|--------------------------------|--------|--------------------------------|--------|
| 21 | 100.0% | 23 | 100.0% | 23 | 100.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 18 | 85.7% | 22 | 95.7% | 22 | 95.7% |
| 3 | 14.3% | 1 | 4.3% | 1 | 4.3% |

| Number of payments | | Number of payments | | Number of payments | |
|--------------------|--|--------------------|--|--------------------|--|
| 108 | | 125 | | 173 | |
| 13 | | 13 | | 12 | |

| Number of drug % of all drug c | | Number of drug % of all drug c | | Number of drug % of all drug c | |
|--------------------------------|--------|--------------------------------|--------|--------------------------------|--------|
| 2 | 100.0% | 1 | 100.0% | 100.0% | 100.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 2 | 100.0% | 1 | 100.0% | 1 | 100.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |

| Number of payments | | Number of payments | | Number of payments | |
|--------------------|--|--------------------|--|--------------------|--|
| 108 | | 125 | | 173 | |
| 0 | | 0 | | 0 | |

Number of drug % of all drug c | Number of drug % of all drug c | Number of drug % of all drug c

| | | | | | | |
|----|---------------------------------|--------|-------------------|--------|-------------------|--------|
| 1 | | | | | | |
| 2 | 72 | 100.0% | 74 | 100.0% | 69 | 100.0% |
| 3 | 4 | 5.6% | 7 | 9.5% | 4 | 5.8% |
| 4 | 5 | 6.9% | 9 | 12.2% | 5 | 7.2% |
| 5 | | | | | | |
| 6 | 12 | 16.7% | 17 | 23.0% | 12 | 17.4% |
| 7 | 34 | 47.2% | 28 | 37.8% | 29 | 42.0% |
| 8 | | | | | | |
| 9 | | | | | | |
| 10 | Number of drug % of all drug (0 | | | | | |
| 11 | 55 | 100.0% | 57 | 100.0% | 50 | 100.0% |
| 12 | 1 | 1.8% | 5 | 8.8% | 3 | 6.0% |
| 13 | | | | | | |
| 14 | 2 | 3.6% | 7 | 12.3% | 4 | 8.0% |
| 15 | 9 | 16.4% | 15 | 26.3% | 11 | 22.0% |
| 16 | 20 | 36.4% | 13 | 22.8% | 11 | 22.0% |
| 17 | | | | | | |
| 18 | | | | | | |
| 19 | Number of drug % of all drug (0 | | | | | |
| 20 | 21 | 100.0% | 23 | 100.0% | 23 | 100.0% |
| 21 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 22 | | | | | | |
| 23 | 1 | 4.8% | 0 | 0.0% | 0 | 0.0% |
| 24 | 3 | 14.3% | 4 | 17.4% | 2 | 8.7% |
| 25 | | | | | | |
| 26 | 2 | 9.5% | 1 | 4.3% | 1 | 4.3% |
| 27 | | | | | | |
| 28 | Number of drug % of all drug (0 | | | | | |
| 29 | 2 | 100.0% | 1 | 100.0% | 100.0% | 100.0% |
| 30 | | | | | | |
| 31 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 32 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 33 | | | | | | |
| 34 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 35 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 36 | | | | | | |
| 37 | | | | | | |
| 38 | | | | | | |
| 39 | | | | | | |
| 40 | Number of drug % of all drug (0 | | | | | |
| 41 | 59 | 100.0% | 60 | 100.0% | 55 | 100.0% |
| 42 | 0 | 0.0% | 1 | 1.7% | 0 | 0.0% |
| 43 | | | | | | |
| 44 | 39 | 66.1% | 41 | 68.3% | 38 | 69.1% |
| 45 | 20 | 33.9% | 18 | 30.0% | 17 | 30.9% |
| 46 | | | | | | |
| 47 | | | | | | |
| 48 | Value of payments | | Value of payments | | Value of payments | |
| 49 | 902,858.00 | | 1,637,974.69 | | 5,986,743.37 | |
| 50 | 2,123,196.45 | | 729,868.42 | | 5,541,099.82 | |
| 51 | | | | | | |
| 52 | | | | | | |
| 53 | Number of drug % of all drug (0 | | | | | |
| 54 | 28 | 100.0% | 30 | 100.0% | 28 | 100.0% |
| 55 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 56 | | | | | | |
| 57 | 21 | 75.0% | 25 | 83.3% | 23 | 82.1% |
| 58 | 7 | 25.0% | 5 | 16.7% | 5 | 17.9% |
| 59 | | | | | | |
| 60 | Value of payments | | Value of payments | | Value of payments | |

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|-------------|-------------|-------------|
| 902,858.0 | 1,637,974.7 | 5,986,743.4 |
| 2,123,196.4 | 729,868.4 | 5,541,099.8 |

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|--------------------------------|--------|---|--------|--------------------------------|--------|---|--------|--------------------------------|-------|---|-------|
| Number of drug % of all drug (| | 0 | | Number of drug % of all drug (| | 0 | | Number of drug % of all drug (| | 0 | |
| 3 | 100.0% | 2 | 100.0% | 2 | 100.0% | 2 | 100.0% | 0 | 0.0% | 0 | 0.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 2 | 66.7% | 2 | 100.0% | 2 | 100.0% | 1 | 50.0% | 1 | 50.0% | 1 | 50.0% |
| 1 | 33.3% | 0 | 0.0% | 0 | 0.0% | 1 | 50.0% | 1 | 50.0% | 1 | 50.0% |

| | | | | | |
|-------------------|-------------|-------------------|-------------|-------------------|-------------|
| Value of payments | | Value of payments | | Value of payments | |
| 902,858.0 | 1,637,974.7 | 5,986,743.4 | 5,986,743.4 | 5,986,743.4 | 5,986,743.4 |
| 2,123,196.4 | - | 5,541,099.8 | 5,541,099.8 | 5,541,099.8 | 5,541,099.8 |

| | | | | | | | | | | | |
|--------------------------------|--------|----|--------|--------------------------------|--------|----|--------|--------------------------------|-------|----|-------|
| Number of drug % of all drug (| | 0 | | Number of drug % of all drug (| | 0 | | Number of drug % of all drug (| | 0 | |
| 59 | 100.0% | 60 | 100.0% | 55 | 100.0% | 55 | 100.0% | 0 | 0.0% | 0 | 0.0% |
| 1 | 1.7% | 5 | 8.3% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 1 | 1.7% | 8 | 13.3% | 4 | 7.3% | 4 | 7.3% | 4 | 7.3% | 4 | 7.3% |
| 8 | 13.6% | 17 | 28.3% | 14 | 25.5% | 14 | 25.5% | 14 | 25.5% | 14 | 25.5% |
| 31 | 52.5% | 24 | 40.0% | 22 | 40.0% | 22 | 40.0% | 22 | 40.0% | 22 | 40.0% |

| | | | | | | | | | | | |
|--------------------------------|--------|----|--------|--------------------------------|--------|----|--------|--------------------------------|-------|----|-------|
| Number of drug % of all drug (| | 0 | | Number of drug % of all drug (| | 0 | | Number of drug % of all drug (| | 0 | |
| 28 | 100.0% | 30 | 100.0% | 28 | 100.0% | 28 | 100.0% | 0 | 0.0% | 0 | 0.0% |
| 1 | 3.6% | 2 | 6.7% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 1 | 3.6% | 2 | 6.7% | 3 | 10.7% | 3 | 10.7% | 3 | 10.7% | 3 | 10.7% |
| 5 | 17.9% | 8 | 26.7% | 10 | 35.7% | 10 | 35.7% | 10 | 35.7% | 10 | 35.7% |
| 8 | 28.6% | 6 | 20.0% | 4 | 14.3% | 4 | 14.3% | 4 | 14.3% | 4 | 14.3% |

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|--------------------------------|--------|---|--------|--------------------------------|--------|---|--------|--------------------------------|------|---|------|
| Number of drug % of all drug (| | 0 | | Number of drug % of all drug (| | 0 | | Number of drug % of all drug (| | 0 | |
| 3 | 100.0% | 2 | 100.0% | 2 | 100.0% | 2 | 100.0% | 0 | 0.0% | 0 | 0.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 1 | 33.3% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |

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companies at a given threshold

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companies at a given threshold

companies at a given threshold

companies

For peer review only

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companies at a given threshold

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For peer review only

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companies at a given threshold

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For peer review only

Web Supplement 5. Recipients - Absolute and relative differences in the number and value of paym

NUMBER OF PAYMENTS

Number of payments - industry data

Number of payments - patient organisation data

Number of patient organisations with at least 1 payment - industry data

Number of patient organisations with at least 1 payment - patient organisation data

NUMBER OF PAYMENTS - THRESHOLDS

Threshold 0: Number of patient organisations with at least 1 one payment in at least one dataset

Threshold 1: Number of patient organisations with more than 1 one payment in at least one dataset

Threshold 2: Number of patient organisations with more than 10 payments in at least one dataset

Threshold 3: Number of patient organisations with more than 100 payments in at least one dataset

NUMBER OF PAYMENTS - ABSOLUTE DIFFERENCES

Number of payments - threshold 0

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Number of payments - threshold 1

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Number of payments - threshold 2

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Number of payments - threshold 3

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Number of patient organisations with exact match in both datasets
 Number of patient organisations with more payments in industry data
 Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi
 Highest absolute difference between patient organisation and industry data - number of payments hi

NUMBER OF PAYMENTS - RELATIVE DIFFERENCES

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 1

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 2

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 3

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES

Value of payments - industry data (2016 £)
 Value of payments - patient organisation data (2016 £)
 Number of payments with value >£0 - industry data
 Number of payments with value >£0 - patient organisation data
 Number of patient organisations with at least one payment with the value >£0 - industry data
 Number of patient organisations with at least one payment with the value >£0 - patient organisation

VALUE OF PAYMENTS - THRESHOLDS

Threshold 1: Number of patient organisations with at least one payment with value >0 in at least one
 Threshold 2: Number of patient organisations with payments with the value of more than £10,000 in
 Threshold 3: Number of patient organisations with payments with the value of more than £100,000 in

VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES

Number of payments - threshold 1

Number of patient organisations with exact match in both datasets

Number of patient organisations with higher payment value in industry data

Number of patient organisations with higher payment value in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Number of payments - threshold 2

Number of patient organisations with exact match in both datasets

Number of patient organisations with higher payment value in industry data

Number of patient organisations with higher payment value in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Number of payments - threshold 3

Number of patient organisations with exact match in both datasets

Number of patient organisations with higher payment value in industry data

Number of patient organisations with higher payment value in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

VALUE OF PAYMENTS - RELATIVE DIFFERENCES

Relative difference <10%

Relative difference <20%

Relative difference <50%

Relative difference = 100%

Number of payments - threshold 1

Relative difference <10%

Relative difference <20%

Relative difference <50%

Relative difference = 100%

Number of payments - threshold 2

Relative difference <10%

Relative difference <20%

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2 Relative difference <50%
3 Relative difference = 100%

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6 **Number of payments - threshold 3**

7 Relative difference <10%
8 Relative difference <20%
9 Relative difference <50%
10 Relative difference = 100%

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| Total | 4316 | | 1 | 1 | 1 | 12 |
| | 1661 | | 0 | 0 | 0 | 0 |
| | 425 | | 1 | 1 | 1 | 1 |
| | 200 | | 0 | 0 | 0 | 0 |
| Number of patient % of all patient organisations with at least one payment in at least one d | | | | | | |
| | 425 | 100.0% | 1 | 1 | 1 | 1 |
| | 299 | 70.4% | | | | 1 |
| | 115 | 27.1% | | | | 1 |
| | 3 | 0.7% | | | | |
| Number of patient % of all patient organisations at a given threshold | | | | | | |
| | 33 | 7.8% | | | | |
| | 335 | 78.8% | 1 | 1 | 1 | 1 |
| | 57 | 13.4% | | | | |
| Number of payments | | | | | | |
| | 199 | | 1 | 1 | 1 | 12 |
| | 33 | | | | | |
| Number of patient % of all patient organisations at a given threshold | | | | | | |
| | 13 | 4.3% | | | | |
| | 229 | 76.6% | | | | 1 |
| | 57 | 19.1% | | | | |
| Number of payments | | | | | | |
| | 199 | | | | | 12 |
| | 33 | | | | | |
| Number of patient % of all patient organisations at a given threshold | | | | | | |
| | 2 | 1.7% | | | | |
| | 95 | 82.6% | | | | 1 |
| | 18 | 15.7% | | | | |
| Number of payments | | | | | | |
| | 199 | | | | | 12 |
| | 33 | | | | | |
| Number of patient % of all patient organisations at a given threshold | | | | | | |

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|----|--|--------|--------|--------|--------|--------|
| 1 | | | | | | |
| 2 | 0 | 0.0% | | | | |
| 3 | 3 | 100.0% | | | | |
| 4 | 0 | 0.0% | | | | |
| 5 | | | | | | |
| 6 | | | | | | |
| 7 | Number of payments | | | | | |
| 8 | 199 | | | | | |
| 9 | 0 | | | | | |
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| 14 | Number of patient % of all patient organisations with at least one payment in at least one d | | | | | |
| 15 | 35 | 8.2% | | | | |
| 16 | 42 | 9.9% | | | | |
| 17 | 81 | 19.1% | | | | |
| 18 | 225 | 52.9% | 100.0% | 100.0% | 100.0% | 100.0% |
| 19 | | | | | | |
| 20 | | | | | | |
| 21 | Number of patient % of all patient organisations at a given threshold | | | | | |
| 22 | 15 | 5.0% | | | | |
| 23 | 22 | 7.4% | | | | |
| 24 | 61 | 20.4% | | | | |
| 25 | 119 | 39.8% | | | | 100.0% |
| 26 | | | | | | |
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| 28 | | | | | | |
| 29 | Number of patient % of all patient organisations at a given threshold | | | | | |
| 30 | 4 | 3.5% | | | | |
| 31 | 7 | 6.1% | | | | |
| 32 | 31 | 27.0% | | | | |
| 33 | 33 | 28.7% | | | | 100.0% |
| 34 | | | | | | |
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| 36 | | | | | | |
| 37 | Number of patient % of all patient organisations at a given threshold | | | | | |
| 38 | 0 | 0.0% | | | | |
| 39 | 0 | 0.0% | | | | |
| 40 | 0 | 0.0% | | | | |
| 41 | 0 | 0.0% | | | | |
| 42 | 1 | 33.3% | | | | |
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| 45 | | | | | | |
| 46 | £54,071,454.2 | | 1029 | 5070 | 101 | 47076 |
| 47 | £33,037,955.8 | | 0 | 0 | 0 | 0 |
| 48 | 4235 | | 1 | 1 | 1 | 12 |
| 49 | 772 | | 0 | 0 | 0 | 0 |
| 50 | 416 | | 1 | 1 | 1 | 1 |
| 51 | 121 | | 0 | 0 | 0 | 0 |
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| 58 | 416 | | 1 | 1 | 1 | 1 |
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| Number of patient % of all patient organisations at a given threshold | | | | | | |
| 8 | 1.9% | | | | | |
| 356 | 85.6% | 1 | 1 | 1 | 1 | |
| 52 | 12.5% | | | | | |
| Vallue of payments | | | | | | |
| 6,718,576.6 | | 0 | 0 | 0 | 0 | |
| 6,493,237.1 | | 1029 | 5070 | 101 | 47076 | |
| Number of patient % of all patient organisations at a given threshold | | | | | | |
| 0 | 0.0% | | | | | |
| 80 | 76.9% | | | | | |
| 24 | 23.1% | | | | | |
| Vallue of payments | | | | | | |
| 6,718,576.6 | | | | | | |
| 6,493,237.1 | | | | | | |
| Number of patient % of all patient organisations at a given threshold | | | | | | |
| 0 | 0.0% | | | | | |
| 6 | 46.2% | | | | | |
| 7 | 53.8% | | | | | |
| Vallue of payments | | | | | | |
| 6,718,576.6 | | | | | | |
| 6,493,237.1 | | | | | | |
| Number of patient % of all patient organisations with at least one payment with value >£0 i | | | | | | |
| 21 | 5.0% | | | | | |
| 34 | 8.2% | | | | | |
| 73 | 17.5% | | | | | |
| 295 | 70.9% | 100.0% | 100.0% | 100.0% | 100.0% | |
| 21 | 5.0% | | | | | |
| 34 | 8.2% | | | | | |
| 73 | 17.5% | | | | | |
| 295 | 70.9% | 100.0% | 100.0% | 100.0% | 100.0% | |
| 4 | 3.8% | | | | | |
| 8 | 7.7% | | | | | |

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| 3 | 54 | 51.9% |
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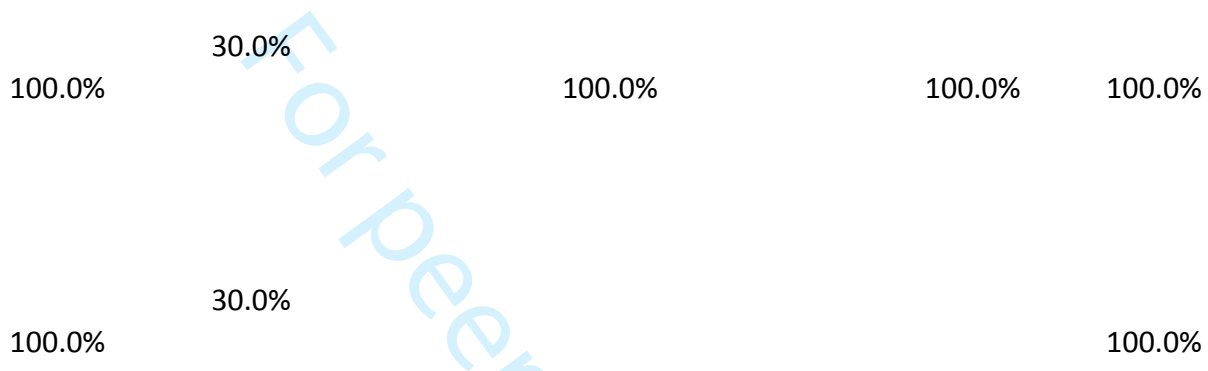
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Anthony Nola Anticoagulation Anxiety UK Aplastic Anaemia Arrhythmia Atrial Arthritis and Osteoarthritis Care

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Children's Health: Children's HIV/AIDS, Chronic Lymphocytic Myeloid Leukemia, Cleft Lip and Palate, and Intellectual Disability

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Coppafeel! Core Charity Crohn's and C Crohn's in ChiCure and ActiCure ParkinscCystic Fibrosis

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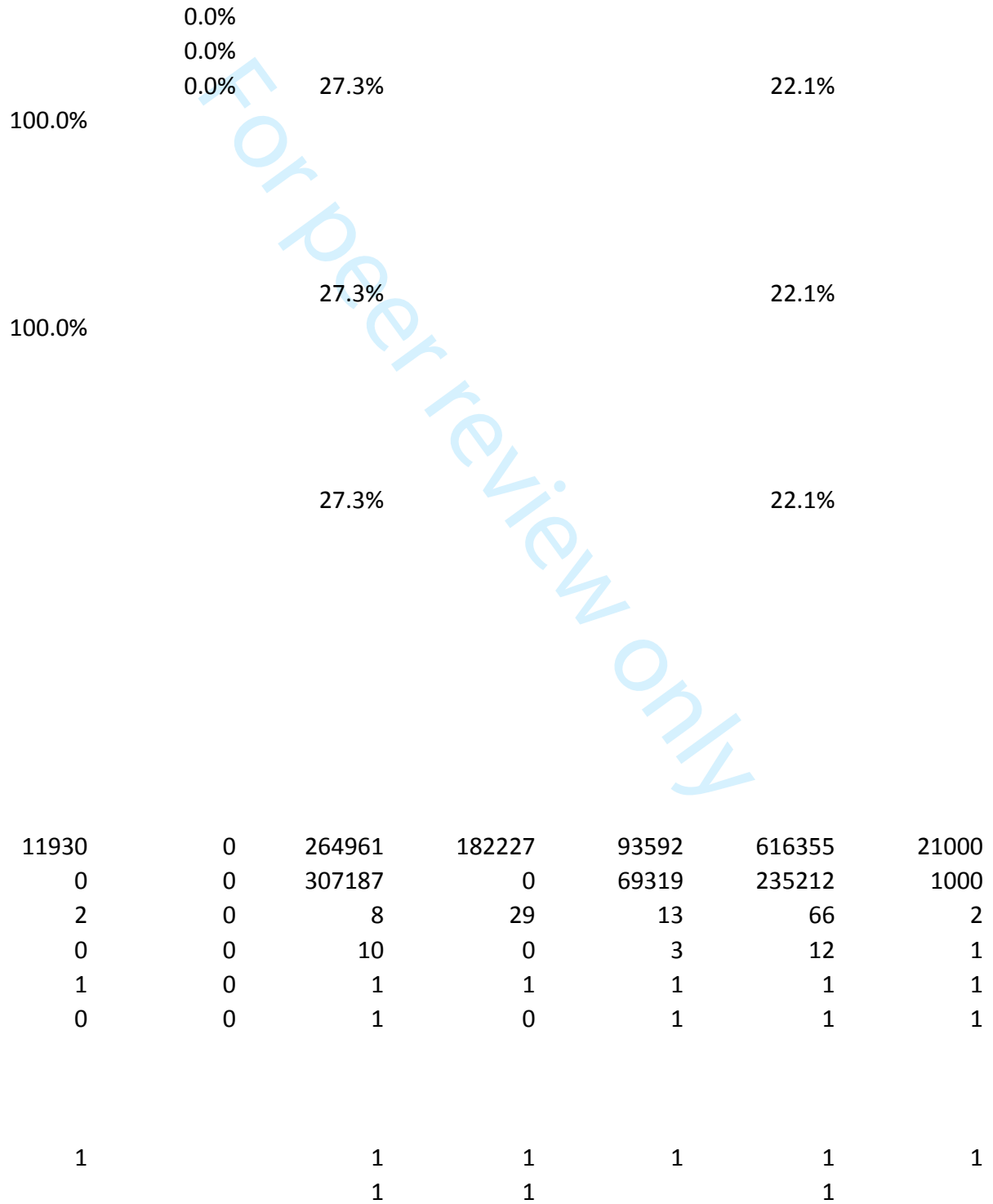
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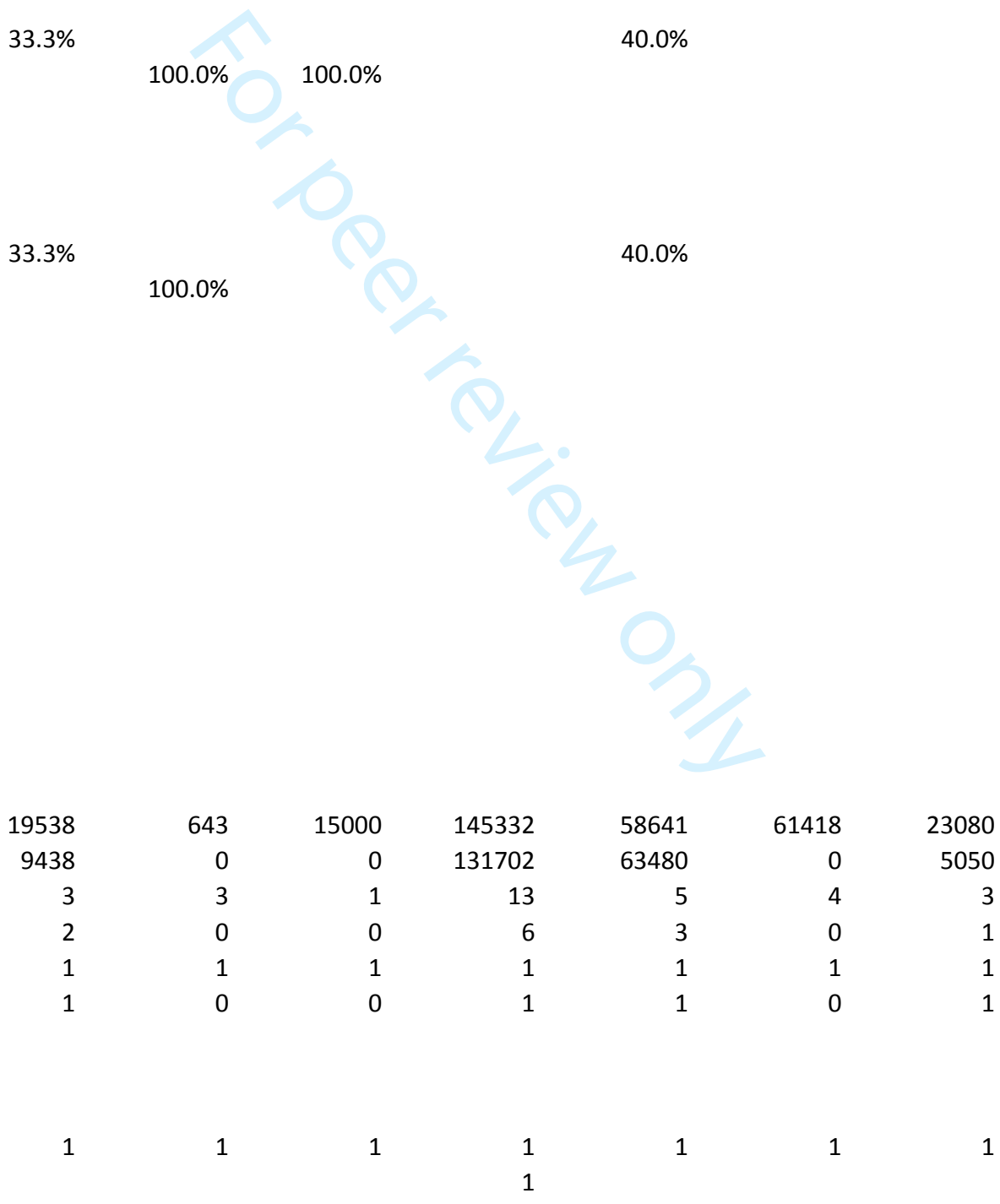
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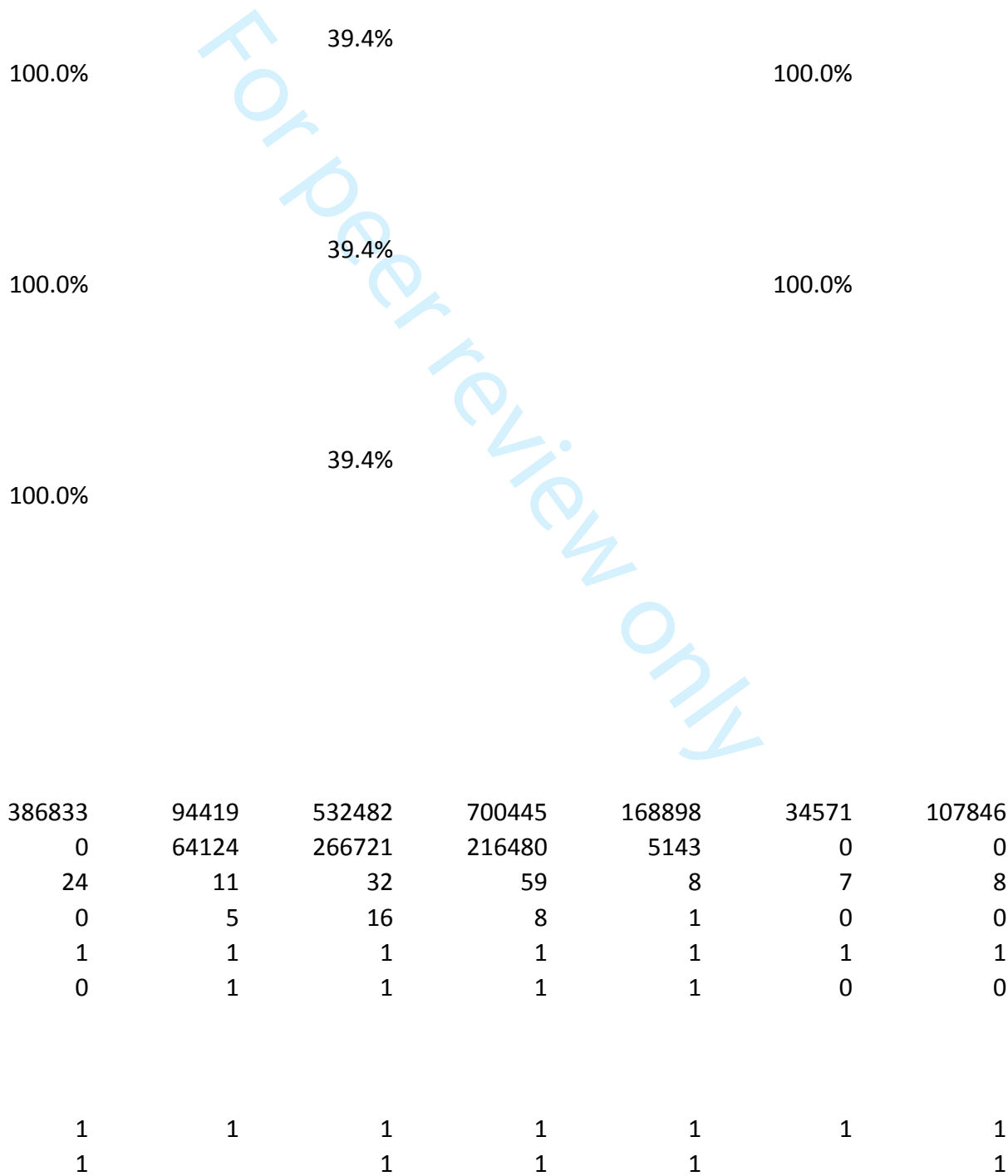
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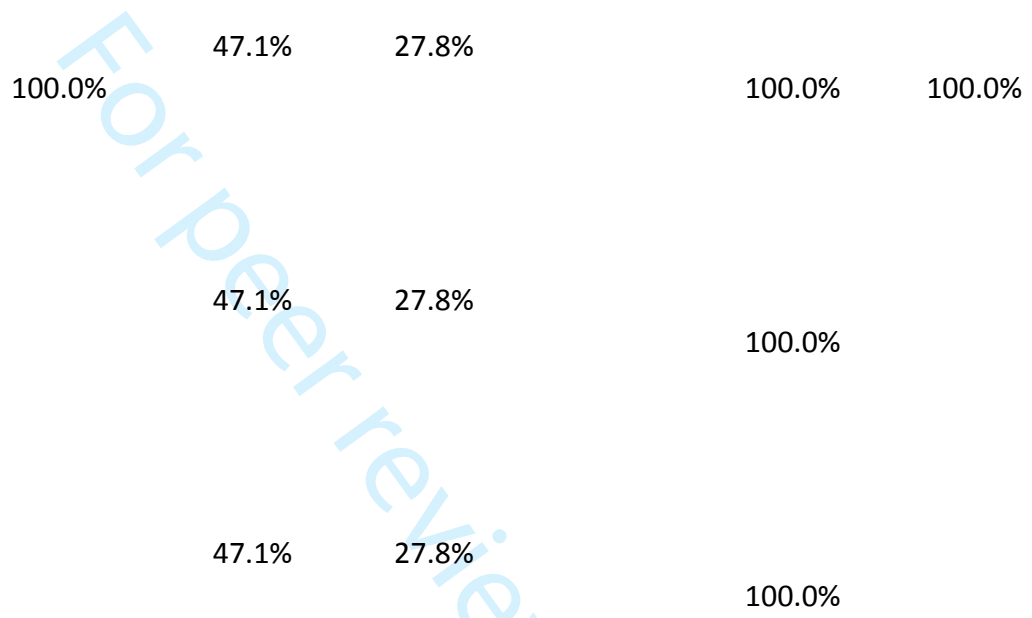
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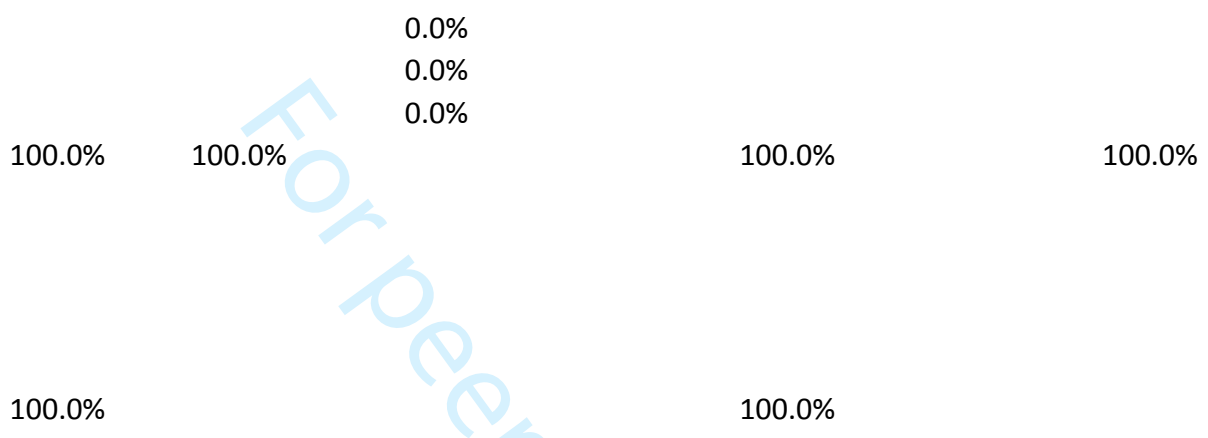
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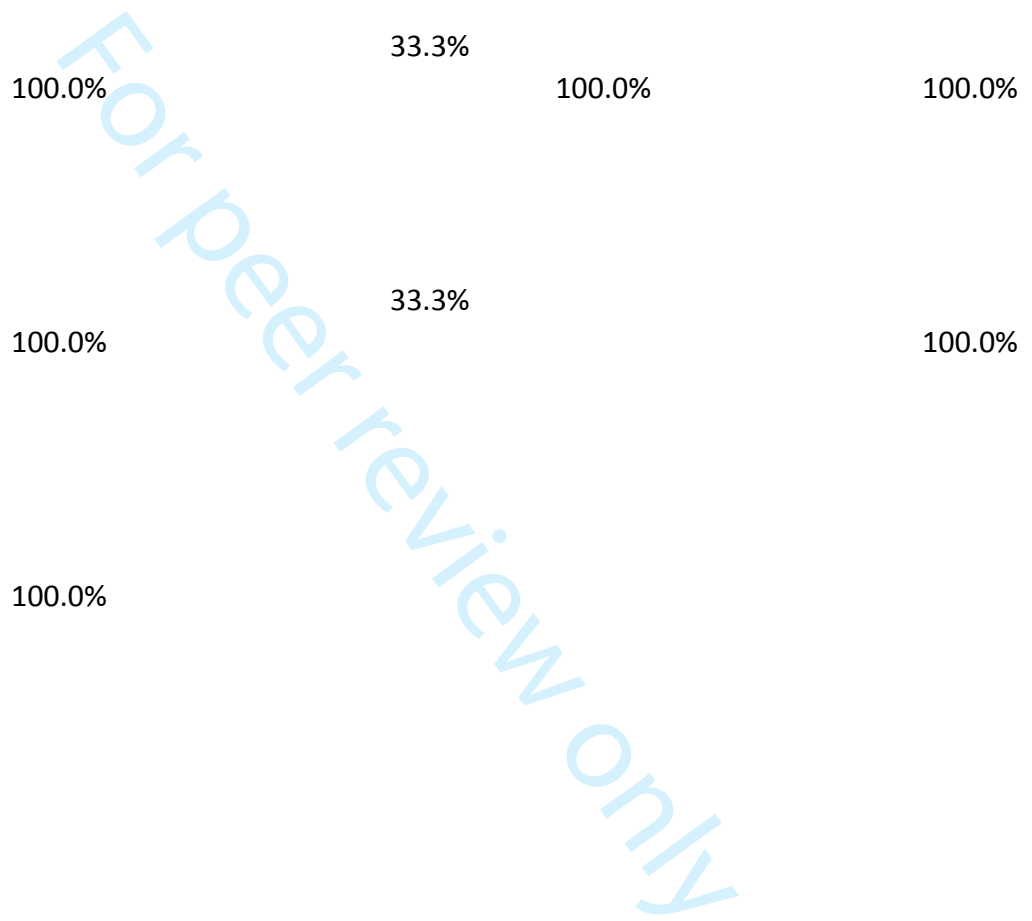
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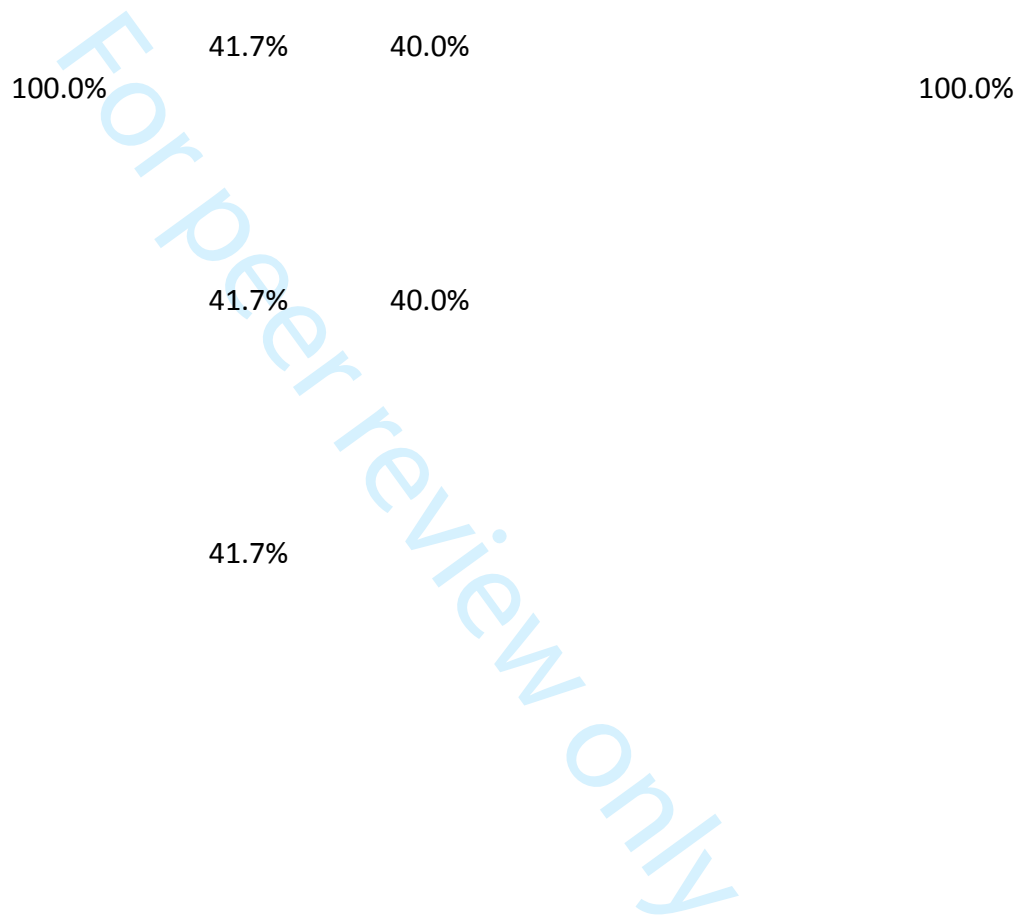
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Web Supplement 6. Recipients - Absolute and relative differences in the number and value of paym**NUMBER OF PAYMENTS - ABSOLUTE DIFFERENCES****Threshold 0: At least 1 one payment in at least one dataset**

Total

Number of patient organisations with exact match in both datasets

Number of patient organisations with more paymens in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Threshold 1: More than 1 one payment in at least one datase

Total

Number of patient organisations with exact match in both datasets

Number of patient organisations with more paymens in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Threshold 2: More than 10 payments in at least one dataset

Total

Number of patient organisations with exact match in both datasets

Number of patient organisations with more paymens in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

Threshold 3: More than 100 payments in at least one dataset

Total

Number of patient organisations with exact match in both datasets

Number of patient organisations with more paymens in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments hi

Highest absolute difference between patient organisation and industry data - number of payments hi

NUMBER OF PAYMENTS - RELATIVE DIFFERENCES**Threshold 0: At least 1 one payment in at least one dataset**

1
2 Total
3 Relative difference <10%
4 Relative difference <20%
5 Relative difference <50%
6 Relative difference = 100%

7
8
9
10 **Threshold 1: More than 1 one payment in at least one dataset**

11 Total
12 Relative difference <10%
13 Relative difference <20%
14 Relative difference <50%
15 Relative difference = 100%

16
17
18
19 **Threshold 2: More than 10 payments in at least one dataset**

20 Total
21 Relative difference <10%
22 Relative difference <20%
23 Relative difference <50%
24 Relative difference = 100%

25
26
27
28 **Threshold 3: More than 100 payments in at least one dataset**

29 Total
30 Relative difference <10%
31 Relative difference <20%
32 Relative difference <50%
33 Relative difference = 100%

34
35
36
37 **VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES**

38
39
40 **Threshold 1: At least one payment with value >£0 in at least one dataset**

41 Total
42 Number of patient organisations with exact match in both datasets
43 Number of patient organisations with higher payment value in industry data
44 Number of patient organisations with higher payment value in patient organisation data

45
46
47
48
49 Highest absolute difference between patient organisation and industry data - number of payments hi
50 Highest absolute difference between patient organisation and industry data - number of payments hi

51
52
53 **Threshold 2: Payments with the value of more than £10,000 in at least one dataset**

54 Total
55 Number of patient organisations with exact match in both datasets
56 Number of patient organisations with higher payment value in industry data
57 Number of patient organisations with higher payment value in patient organisation data

1
2 Highest absolute difference between patient organisation and industry data - number of payments hi
3 Highest absolute difference between patient organisation and industry data - number of payments hi
4

5
6 **Threshold 3: Payments with the value of more than £100,000 in at least one dataset**

7 Total

8 Number of patient organisations with exact match in both datasets

9 Number of patient organisations with higher payment value in industry data

10 Number of patient organisations with higher payment value in patient organisation data
11
12
13
14

15 Highest absolute difference between patient organisation and industry data - number of payments hi

16 Highest absolute difference between patient organisation and industry data - number of payments hi
17
18

19 **VALUE OF PAYMENTS - RELATIVE DIFFERENCES**
20

21 **Threshold 1: At least one payment with value >£0 in at least one dataset**

22 Total

23 Relative difference <10%

24 Relative difference <20%

25 Relative difference <50%

26 Relative difference = 100%
27
28
29
30

31 **Threshold 2: Payments with the value of more than £10,000 in at least one dataset**

32 Total

33 Relative difference <10%

34 Relative difference <20%

35 Relative difference <50%

36 Relative difference = 100%
37
38
39

40 **Threshold 3: Payments with the value of more than £100,000 in at least one dataset**

41 Total

42 Relative difference <10%

43 Relative difference <20%

44 Relative difference <50%

45 Relative difference = 100%
46
47
48
49
50
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| All years | | 2012 | | 2013 | |
|--------------------|-------------------|--------------------|-------------------|--------------------|-------------------|
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |
| 425 | 100.0% | 219 | 100.0% | 225 | 100.0% |
| 33 | 7.8% | 17 | 7.8% | 18 | 8.0% |
| 335 | 78.8% | 160 | 73.1% | 157 | 69.8% |
| 57 | 13.4% | 42 | 19.2% | 50 | 22.2% |
| Number of payments | | Number of payments | | Number of payments | |
| 199 | | 36 | | 35 | |
| 33 | | 9 | | 17 | |
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |
| 299 | 100.0% | 140 | 100.0% | 137 | 100.0% |
| 13 | 4.3% | 6 | 4.3% | 9 | 6.6% |
| 229 | 76.6% | 105 | 75.0% | 95 | 69.3% |
| 57 | 19.1% | 29 | 20.7% | 33 | 24.1% |
| Number of payments | | Number of payments | | Number of payments | |
| 199 | | 36 | | 35 | |
| 33 | | 9 | | 17 | |
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |
| 115 | 100.0% | 20 | 100.0% | 13 | 100.0% |
| 2 | 1.7% | 1 | 5.0% | 0 | 0.0% |
| 95 | 82.6% | 16 | 80.0% | 9 | 69.2% |
| 18 | 15.7% | 3 | 15.0% | 4 | 30.8% |
| Number of payments | | Number of payments | | Number of payments | |
| 199 | | 36 | | 35 | |
| 33 | | 9 | | 17 | |
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |
| 3 | 100.0% | 0 | N/A | 0 | N/A |
| 0 | 0.0% | N/A | N/A | N/A | N/A |
| 3 | 100.0% | N/A | N/A | N/A | N/A |
| 0 | 0.0% | N/A | N/A | N/A | N/A |
| Number of payments | | Number of payments | | Number of payments | |
| 199 | | 0 | | 0 | |
| 0 | | 0 | | 0 | |
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |

| | | | | | | |
|----|--|--------|-------------------|--------|-------------------|--------|
| 1 | | | | | | |
| 2 | 425 | 100.0% | 219 | 100.0% | 225 | 100.0% |
| 3 | 35 | 8.2% | 17 | 7.8% | 18 | 8.0% |
| 4 | 42 | 9.9% | 18 | 8.2% | 19 | 8.4% |
| 5 | 81 | 19.1% | 30 | 13.7% | 34 | 15.1% |
| 6 | 225 | 52.9% | 138 | 63.0% | 150 | 66.7% |
| 7 | | | | | | |
| 8 | | | | | | |
| 9 | | | | | | |
| 10 | Number of pat % of all patient cNumber of pai% of all patient cNumber of pai% of all patient c | | | | | |
| 11 | 299 | 100.0% | 140 | 100.0% | 137 | 100.0% |
| 12 | 15 | 5.0% | 6 | 4.3% | 9 | 6.6% |
| 13 | 22 | 7.4% | 7 | 5.0% | 10 | 7.3% |
| 14 | 61 | 20.4% | 19 | 13.6% | 25 | 18.2% |
| 15 | 119 | 39.8% | 70 | 50.0% | 71 | 51.8% |
| 16 | | | | | | |
| 17 | | | | | | |
| 18 | | | | | | |
| 19 | Number of pat % of all patient cNumber of pai% of all patient cNumber of pai% of all patient c | | | | | |
| 20 | 115 | 100.0% | 20 | 100.0% | 13 | 100.0% |
| 21 | 4 | 3.5% | 1 | 5.0% | 0 | 0.0% |
| 22 | 7 | 6.1% | 2 | 10.0% | 0 | 0.0% |
| 23 | 31 | 27.0% | 4 | 20.0% | 1 | 7.7% |
| 24 | 33 | 28.7% | 7 | 35.0% | 5 | 38.5% |
| 25 | | | | | | |
| 26 | | | | | | |
| 27 | | | | | | |
| 28 | Number of pat % of all patient cNumber of pai% of all patient cNumber of pai% of all patient c | | | | | |
| 29 | 3 | 100.0% | 0 | N/A | 0 | N/A |
| 30 | 0 | 0.0% | N/A | N/A | N/A | N/A |
| 31 | 0 | 0.0% | N/A | N/A | N/A | N/A |
| 32 | 0 | 0.0% | N/A | N/A | N/A | N/A |
| 33 | 1 | 33.3% | N/A | N/A | N/A | N/A |
| 34 | | | | | | |
| 35 | | | | | | |
| 36 | | | | | | |
| 37 | | | | | | |
| 38 | | | | | | |
| 39 | | | | | | |
| 40 | Number of pat % of all patient cNumber of pai% of all patient cNumber of pai% of all patient c | | | | | |
| 41 | 416 | 100.0% | 206 | 100.0% | 204 | 100.0% |
| 42 | 8 | 1.9% | 4 | 1.9% | 4 | 2.0% |
| 43 | 356 | 85.6% | 168 | 81.6% | 164 | 80.4% |
| 44 | 52 | 12.5% | 34 | 16.5% | 36 | 17.6% |
| 45 | | | | | | |
| 46 | | | | | | |
| 47 | | | | | | |
| 48 | Value of payments | | Value of payments | | Value of payments | |
| 49 | 6,718,576.6 | | 660,846.1 | | 369,657.9 | |
| 50 | 6,493,237.1 | | 283,684.7 | | 829,991.7 | |
| 51 | | | | | | |
| 52 | | | | | | |
| 53 | Number of pat % of all patient cNumber of pai% of all patient cNumber of pai% of all patient c | | | | | |
| 54 | 104 | 100.0% | 29 | 100.0% | 20 | 100.0% |
| 55 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 56 | 80 | 76.9% | 19 | 65.5% | 12 | 60.0% |
| 57 | 24 | 23.1% | 10 | 34.5% | 8 | 40.0% |
| 58 | | | | | | |
| 59 | | | | | | |
| 60 | Value of payments | | Value of payments | | Value of payments | |

| | | | | | | |
|--|--------|-----|-----------|--------|--|-----------|
| 6,718,576.6 | | | 660,846.1 | | | 369,657.9 |
| 6,493,237.1 | | | 283,684.7 | | | 829,991.7 |
| Number of pat % of all patient cNumber of pai% of all patient cNumber of pai% of all patient c | | | | | | |
| 13 | 100.0% | | 0 | N/A | | 0 |
| 0 | 0.0% | N/A | | N/A | | N/A |
| 6 | 46.2% | N/A | | N/A | | N/A |
| 7 | 53.8% | N/A | | N/A | | N/A |
| Value of payments | | | | | | |
| 6,718,576.6 | | | - | | | - |
| 6,493,237.1 | | | - | | | - |
| Number of pat % of all patient cNumber of pai% of all patient cNumber of pai% of all patient c | | | | | | |
| 416 | 100.0% | | 206 | 100.0% | | 204 |
| 21 | 5.0% | | 6 | 2.9% | | 8 |
| 34 | 8.2% | | 11 | 5.3% | | 13 |
| 73 | 17.5% | | 20 | 9.7% | | 21 |
| 295 | 70.9% | | 158 | 76.7% | | 164 |
| Number of pat % of all patient cNumber of pai% of all patient cNumber of pai% of all patient c | | | | | | |
| 104 | 100.0% | | 29 | 100.0% | | 20 |
| 4 | 3.8% | | 0 | 0.0% | | 0 |
| 8 | 7.7% | | 2 | 6.9% | | 0 |
| 23 | 22.1% | | 4 | 13.8% | | 2 |
| 54 | 51.9% | | 17 | 58.6% | | 11 |
| Number of pat % of all patient cNumber of pai% of all patient cNumber of pai% of all patient c | | | | | | |
| 13 | 100.0% | | 0 | N/A | | 0 |
| 0 | 0.0% | N/A | | N/A | | N/A |
| 0 | 0.0% | N/A | | N/A | | N/A |
| 3 | 23.1% | N/A | | N/A | | N/A |
| 4 | 30.8% | N/A | | N/A | | N/A |

| | 2014 | | 2015 | | 2016 |
|--------------------|------|-------------------|--------------------|-------------------|--------------------|
| Number of patients | | % of all patients | | % of all patients | organisation |
| | 247 | 100.0% | 267 | 100.0% | 260 |
| | 29 | 11.7% | 31 | 11.6% | 21 |
| | 173 | 70.0% | 186 | 69.7% | 208 |
| | 45 | 18.2% | 50 | 18.7% | 31 |
| Number of payments | | | Number of payments | | Number of payments |
| | 36 | | 44 | | 55 |
| | 15 | | 10 | | 11 |
| Number of patients | | % of all patients | | % of all patients | organisation |
| | 146 | 100.0% | 149 | 100.0% | 166 |
| | 6 | 4.1% | 8 | 5.4% | 7 |
| | 110 | 75.3% | 107 | 71.8% | 138 |
| | 30 | 20.5% | 34 | 22.8% | 21 |
| Number of payments | | | Number of payments | | Number of payments |
| | 36 | | 44 | | 55 |
| | 15 | | 10 | | 11 |
| Number of patients | | % of all patients | | % of all patients | organisation |
| | 15 | 100.0% | 22 | 100.0% | 29 |
| | 0 | 0.0% | 0 | 0.0% | 0 |
| | 11 | 73.3% | 19 | 86.4% | 26 |
| | 4 | 26.7% | 3 | 13.6% | 3 |
| Number of payments | | | Number of payments | | Number of payments |
| | 36 | | 44 | | 55 |
| | 15 | | 10 | | 11 |
| Number of patients | | % of all patients | | % of all patients | organisation |
| | 0 | N/A | 0 | N/A | 0 |
| | N/A | N/A | N/A | N/A | N/A |
| | N/A | N/A | N/A | N/A | N/A |
| | N/A | N/A | N/A | N/A | N/A |
| Number of payments | | | Number of payments | | Number of payments |
| | 0 | | 0 | | 0 |
| | 0 | | 0 | | 0 |
| Number of patients | | % of all patients | | % of all patients | organisation |

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| | | | | |
|-----|--------|-----|--------|-----|
| 247 | 100.0% | 267 | 100.0% | 260 |
| 29 | 11.7% | 31 | 11.6% | 21 |
| 32 | 13.0% | 33 | 12.4% | 24 |
| 48 | 19.4% | 49 | 18.4% | 45 |
| 153 | 61.9% | 164 | 61.4% | 159 |

| Number of patients | % of all patients | Number of patients | % of all patients | organisation | Number of patients |
|--------------------|-------------------|--------------------|-------------------|--------------|--------------------|
| 146 | 100.0% | 149 | 100.0% | | 166 |
| 6 | 4.1% | 8 | 5.4% | | 7 |
| 9 | 6.2% | 10 | 6.7% | | 10 |
| 25 | 17.1% | 26 | 17.4% | | 31 |
| 75 | 51.4% | 69 | 46.3% | | 79 |

| Number of patients | % of all patients | Number of patients | % of all patients | organisation | Number of patients |
|--------------------|-------------------|--------------------|-------------------|--------------|--------------------|
| 15 | 100.0% | 22 | 100.0% | | 29 |
| 0 | 0.0% | 0 | 0.0% | | 0 |
| 1 | 6.7% | 1 | 4.5% | | 1 |
| 3 | 20.0% | 4 | 18.2% | | 6 |
| 5 | 33.3% | 7 | 31.8% | | 13 |

| Number of patients | % of all patients | Number of patients | % of all patients | organisation | Number of patients |
|--------------------|-------------------|--------------------|-------------------|--------------|--------------------|
| 0 | N/A | 0 | N/A | | 0 |
| N/A | N/A | N/A | N/A | | N/A |
| N/A | N/A | N/A | N/A | | N/A |
| N/A | N/A | N/A | N/A | | N/A |
| N/A | N/A | N/A | N/A | | N/A |

| Number of patients | % of all patients | Number of patients | % of all patients | organisation | Number of patients |
|--------------------|-------------------|--------------------|-------------------|--------------|--------------------|
| 234 | 100.0% | 249 | 100.0% | | 249 |
| 11 | 4.7% | 15 | 6.0% | | 8 |
| 196 | 83.8% | 198 | 79.5% | | 211 |
| 27 | 11.5% | 36 | 14.5% | | 30 |

| Value of payments | Value of payments | Value of payments |
|-------------------|-------------------|-------------------|
| 538,969.2 | 1,473,965.2 | 6,006,677.7 |
| 1,824,997.0 | 815,956.8 | 6,493,237.1 |

| Number of patients | % of all patients | Number of patients | % of all patients | organisation | Number of patients |
|--------------------|-------------------|--------------------|-------------------|--------------|--------------------|
| 31 | 100.0% | 34 | 100.0% | | 36 |
| 0 | 0.0% | 0 | 0.0% | | 0 |
| 24 | 77.4% | 25 | 73.5% | | 25 |
| 7 | 22.6% | 9 | 26.5% | | 11 |

| Value of payments | Value of payments | Value of payments |
|-------------------|-------------------|-------------------|
|-------------------|-------------------|-------------------|

| | | | | | |
|----|--------------------|-------------------|--------------------|-------------------|-------------------|
| 1 | | | | | |
| 2 | 538,969.2 | | 1,473,965.2 | | 6,006,677.7 |
| 3 | 1,824,997.0 | | 815,956.8 | | 6,493,237.1 |
| 4 | | | | | |
| 5 | | | | | |
| 6 | Number of patients | % of all patients | Number of patients | % of all patients | organisation |
| 7 | 1 | 100.0% | 1 | 100.0% | 2 |
| 8 | 0 | 0.0% | 0 | 0.0% | 0 |
| 9 | 0 | 0.0% | 1 | 100.0% | 1 |
| 10 | 0 | 0.0% | 1 | 100.0% | 1 |
| 11 | 1 | 100.0% | 0 | 0.0% | 1 |
| 12 | | | | | |
| 13 | | | | | |
| 14 | Value of payments | | Value of payments | | Value of payments |
| 15 | - | | 1,473,965.24 | | 6,006,677.66 |
| 16 | 1,824,996.99 | | - | | 6,493,237.05 |
| 17 | | | | | |
| 18 | | | | | |
| 19 | | | | | |
| 20 | | | | | |
| 21 | | | | | |
| 22 | Number of patients | % of all patients | Number of patients | % of all patients | organisation |
| 23 | 234 | 100.0% | 249 | 100.0% | 249 |
| 24 | 16 | 6.8% | 20 | 8.0% | 18 |
| 25 | 19 | 8.1% | 25 | 10.0% | 26 |
| 26 | 19 | 8.1% | 25 | 10.0% | 26 |
| 27 | 28 | 12.0% | 39 | 15.7% | 36 |
| 28 | 185 | 79.1% | 189 | 75.9% | 197 |
| 29 | | | | | |
| 30 | | | | | |
| 31 | Number of patients | % of all patients | Number of patients | % of all patients | organisation |
| 32 | 31 | 100.0% | 34 | 100.0% | 36 |
| 33 | 1 | 3.2% | 0 | 0.0% | 2 |
| 34 | 1 | 3.2% | 0 | 0.0% | 2 |
| 35 | 2 | 6.5% | 0 | 0.0% | 4 |
| 36 | 5 | 16.1% | 5 | 14.7% | 8 |
| 37 | 20 | 64.5% | 21 | 61.8% | 20 |
| 38 | | | | | |
| 39 | | | | | |
| 40 | Number of patients | % of all patients | Number of patients | % of all patients | organisation |
| 41 | 1 | 100.0% | 1 | 100.0% | 2 |
| 42 | 0 | 0.0% | 0 | 0.0% | 0 |
| 43 | 0 | 0.0% | 0 | 0.0% | 0 |
| 44 | 0 | 0.0% | 0 | 0.0% | 0 |
| 45 | 0 | 0.0% | 0 | 0.0% | 0 |
| 46 | 0 | 0.0% | 0 | 0.0% | 0 |
| 47 | 0 | 0.0% | 1 | 100.0% | 0 |
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| 60 | | | | | |

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6 % of all patient organisationsa given threshold

7 100.0%

8 8.1%

9 80.0%

10 11.9%

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14 nents

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18
19 % of all patient organisationsa given threshold

20 100.0%

21 4.2%

22 83.1%

23 12.7%

24
25
26
27 nents

28
29
30
31
32 % of all patient organisationsa given threshold

33 100.0%

34 0.0%

35 89.7%

36 10.3%

37
38
39
40 nents

41
42
43
44
45 % of all patient organisationsa given threshold

46 N/A

47 N/A

48 N/A

49 N/A

50
51
52
53 nents

54
55
56
57
58
59
60 % of all patient organisationsa given threshold

| | |
|----|---|
| 1 | |
| 2 | 100.0% |
| 3 | 8.1% |
| 4 | 9.2% |
| 5 | |
| 6 | 17.3% |
| 7 | 61.2% |
| 8 | |
| 9 | |
| 10 | % of all patient organisationsa given threshold |
| 11 | 100.0% |
| 12 | 4.2% |
| 13 | 6.0% |
| 14 | 18.7% |
| 15 | 47.6% |
| 16 | |
| 17 | |
| 18 | |
| 19 | % of all patient organisationsa given threshold |
| 20 | 100.0% |
| 21 | 0.0% |
| 22 | 3.4% |
| 23 | 20.7% |
| 24 | 44.8% |
| 25 | |
| 26 | |
| 27 | |
| 28 | % of all patient organisationsa given threshold |
| 29 | N/A |
| 30 | N/A |
| 31 | N/A |
| 32 | N/A |
| 33 | N/A |
| 34 | N/A |
| 35 | N/A |
| 36 | |
| 37 | |
| 38 | |
| 39 | |
| 40 | % of all patient organisationsa given threshold |
| 41 | 100.0% |
| 42 | 3.2% |
| 43 | 84.7% |
| 44 | 12.0% |
| 45 | |
| 46 | |
| 47 | |
| 48 | nts |
| 49 | |
| 50 | |
| 51 | |
| 52 | |
| 53 | % of all patient organisationsa given threshold |
| 54 | 100.0% |
| 55 | 0.0% |
| 56 | 69.4% |
| 57 | 30.6% |
| 58 | |
| 59 | |
| 60 | |
| | nts |

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4
5
6 % of all patient organisationsa given threshold

7 100.0%

8 0.0%

9 50.0%

10 50.0%

11
12
13
14 nts

15
16
17
18
19
20
21
22 % of all patient organisationsa given threshold

23 100.0%

24 7.2%

25 10.4%

26 14.5%

27 79.1%

28
29
30
31 % of all patient organisationsa given threshold

32 100.0%

33 5.6%

34 11.1%

35 22.2%

36 55.6%

37
38
39
40 % of all patient organisationsa given threshold

41 100.0%

42 0.0%

43 0.0%

44 0.0%

45 0.0%

46 0.0%

Web Supplement 7. Donors - summary of payments missing from i

Year

2012

2013

2014

2015

2016

Total missing - calculated annually

Total missing - calculated for all years

For peer review only

Industry data**Number of companies missing from industry data**

31

30

27

23

0

N/A**24**

For peer review only

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Companies missing from industry dataset as a share of companies in industry d

103.3%
78.9%
60.0%
45.1%
0.0%

N/A
38.1%

For peer review only

Number of payments missing from industry data

| | |
|------------|--------------|
| 124 | 16.1% |
| 131 | 18.6% |
| 74 | 9.0% |
| 52 | 5.6% |
| 54 | 5.0% |
| 435 | 10.1% |
| 128 | 3.0% |

For peer review only

Value of payments missing from industry data (Value of payments missing from industr

| | |
|--------------------|--------------|
| 1,731,257.8 | 22.2% |
| 2,666,247.8 | 43.1% |
| 218,768.4 | 2.5% |
| 1,367,440.0 | 12.0% |
| 474,975.0 | 2.4% |
| 6,458,689.1 | 11.9% |
| 1,610,321.1 | 3.0% |

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ry datas as a share of payments in industry datas

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Web Supplement 8. Donors - payments missing from industry data (year

| Year | Drug company name | Number of payments |
|------|-------------------------|--------------------|
| | Alcon | 3 |
| | Alexion | 1 |
| | ApoPharma | 1 |
| | Baxter | 7 |
| | Bayer | 8 |
| | BioMarin | 1 |
| | Biotest | 1 |
| | Boehringer Ingelheim | 2 |
| | Dermal | 3 |
| | Eisai | 1 |
| | Flynn Pharma | 1 |
| | Fresenius Medical Care | 1 |
| | Genzyme | 9 |
| | Gilead | 8 |
| | GSK | 18 |
| 2012 | Ipsen | 3 |
| | Janssen | 12 |
| | LEO Pharma | 2 |
| | Norgine | 1 |
| | Novo Nordisk | 3 |
| | Octapharma | 1 |
| | Pharma Mar | 1 |
| | RB | 1 |
| | Roche Products | 13 |
| | Sanofi Pasteur MSD | 1 |
| | Sigma Tau Rare Diseases | 1 |
| | Sobi | 1 |
| | Takeda | 6 |
| | Teva | 5 |
| | UCB | 7 |
| | Veriton | 1 |
| | Alcon | 4 |
| | Alexion | 2 |
| | Almirall | 2 |
| | Amdipharm | 1 |
| | ApoPharma | 3 |
| | Bausch and Lomb | 2 |
| | Baxter | 3 |
| | Bayer | 9 |
| | Britannia | 1 |
| | Dermal | 3 |
| | Gedeon Richter | 1 |
| | Genzyme | 9 |
| | Gilead | 10 |

| | | | |
|----|------|--------------------------|----|
| 1 | | | |
| 2 | | GSK | 16 |
| 3 | | Ipsen | 2 |
| 4 | 2013 | IQVIA | 1 |
| 5 | | Janssen | 13 |
| 6 | | LEO Pharma | 4 |
| 7 | | Lundbeck | 1 |
| 8 | | Meda | 1 |
| 9 | | Merck | 8 |
| 10 | | Norgine | 2 |
| 11 | | Orphan Europe | 1 |
| 12 | | PTC | 2 |
| 13 | | RB | 2 |
| 14 | | Roche Products | 14 |
| 15 | | Sigma Tau Rare Diseases | 2 |
| 16 | | Takeda | 9 |
| 17 | | Veriton | 1 |
| 18 | | Vifor Pharma Group | 2 |
| 19 | | Actavis | 1 |
| 20 | | Alcon | 1 |
| 21 | | Alexion | 5 |
| 22 | | Alliance | 1 |
| 23 | | Amdipharm | 1 |
| 24 | | ApoPharma | 1 |
| 25 | | Baxter | 2 |
| 26 | | Bayer | 4 |
| 27 | | Britannia | 1 |
| 28 | | Dermal | 2 |
| 29 | | Gedeon Richter | 1 |
| 30 | | Genzyme | 13 |
| 31 | | GSK | 12 |
| 32 | 2014 | Ipsen | 2 |
| 33 | | Meda | 1 |
| 34 | | Mitsubishi Tanabe Pharma | 1 |
| 35 | | Norgine | 2 |
| 36 | | Novo Nordisk | 4 |
| 37 | | Orion Pharma | 1 |
| 38 | | PTC | 2 |
| 39 | | Rosemont Pharmaceuticals | 1 |
| 40 | | Sigma Tau Rare Diseases | 2 |
| 41 | | Stirling Anglian | 1 |
| 42 | | Syner-Med | 2 |
| 43 | | Teva | 6 |
| 44 | | Veriton | 2 |
| 45 | | Vifor Pharma Group | 2 |
| 46 | | Actavis | 2 |
| 47 | | Aegerion | 1 |
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|----|------|-------------------------|----|
| 1 | | | |
| 2 | | ALK-Abello | 1 |
| 3 | | Amdipharm | 1 |
| 4 | | Bausch and Lomb | 1 |
| 5 | | Britannia | 1 |
| 6 | | Dermal | 3 |
| 7 | | Fresenius Medical Care | 1 |
| 8 | | Genzyme | 9 |
| 9 | | GSK | 13 |
| 10 | | HRA Pharma | 1 |
| 11 | | Norgine | 3 |
| 12 | 2015 | Octapharma | 2 |
| 13 | | Orphan Europe | 1 |
| 14 | | Pharma Mar | 1 |
| 15 | | PTC | 1 |
| 16 | | RB | 1 |
| 17 | | Sanofi Pasteur MSD | 1 |
| 18 | | Santen | 1 |
| 19 | | Sigma Tau Rare Diseases | 2 |
| 20 | | Syner-Med | 1 |
| 21 | | Thea | 1 |
| 22 | | Vifor Pharma Group | 3 |
| 23 | | Meda | 1 |
| 24 | | ALK-Abello | 1 |
| 25 | | Bausch and Lomb | 1 |
| 26 | | Genzyme | 12 |
| 27 | | HRA Pharma | 1 |
| 28 | | BioMarin | 4 |
| 29 | | Allergan | 5 |
| 30 | | Napp Pharmaceuticals | 2 |
| 31 | | Amdipharm | 1 |
| 32 | | Alexion | 4 |
| 33 | | Orphan Europe | 1 |
| 34 | | Ferring | 6 |
| 35 | 2016 | Britannia | 1 |
| 36 | | Aegerion | 1 |
| 37 | | Baxalta | 1 |
| 38 | | Diurnal | 1 |
| 39 | | PTC | 1 |
| 40 | | Bio Products Laboratory | 1 |
| 41 | | Octapharma | 2 |
| 42 | | Sigma Tau Rare Diseases | 1 |
| 43 | | Baxter | 1 |
| 44 | | Fresenius Medical Care | 1 |
| 45 | | Jazz | 1 |
| 46 | | Mylan | 1 |
| 47 | | Dermal | 2 |
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8 170239.7
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10 205156.3
11 0.0
12 22480.9
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14 9468.8
15 0.0
16 0.0
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18 2104.2
19 7890.6
20 116178.4
21
22 50500.0
23 501114.7
24 25250.0
25
26 50804.1
27 0.0
28 0.0
29 0.0
30
31 134882.3
32 6312.5
33 83114.6
34 237981.3
35 20989.1
36
37 0.0
38
39 1052.1
40 23145.8
41 15248.9
42 5260.4
43
44 0.0
45 64796.3
46 5142.6
47
48 0.0
49 0.0
50
51 22627.3
52 22627.3
53 135138.4
54 299046.4
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56 0.0
57 0.0
58 0.0
59
60 278174.8
116016.3

| | |
|----|-----------|
| 1 | |
| 2 | 406794.5 |
| 3 | 20570.3 |
| 4 | 0.0 |
| 5 | 0.0 |
| 6 | 42110.4 |
| 7 | 0.0 |
| 8 | 0.0 |
| 9 | 0.0 |
| 10 | 0.0 |
| 11 | 238799.2 |
| 12 | 0.0 |
| 13 | 0.0 |
| 14 | 1028.5 |
| 15 | 0.0 |
| 16 | 30855.4 |
| 17 | 126301.4 |
| 18 | 514.3 |
| 19 | 4695.2 |
| 20 | 0.0 |
| 21 | 0.0 |
| 22 | 0.0 |
| 23 | 851009.3 |
| 24 | 0.0 |
| 25 | 0.0 |
| 26 | 0.0 |
| 27 | 15210.8 |
| 28 | 0.0 |
| 29 | 18253.0 |
| 30 | 30421.7 |
| 31 | 70948.4 |
| 32 | 27301.4 |
| 33 | 0.0 |
| 34 | 0.0 |
| 35 | 0.0 |
| 36 | 0.0 |
| 37 | 0.0 |
| 38 | 0.0 |
| 39 | 225781.6 |
| 40 | 2123196.4 |
| 41 | 34873.4 |
| 42 | 0.0 |
| 43 | 0.0 |
| 44 | 5070.3 |
| 45 | 16884.0 |
| 46 | 16144.8 |
| 47 | 0.0 |
| 48 | 0.0 |
| 49 | 0.0 |
| 50 | 0.0 |
| 51 | 0.0 |
| 52 | 28869.2 |
| 53 | 0.0 |
| 54 | 0.0 |
| 55 | 0.0 |
| 56 | 7098.4 |
| 57 | 0.0 |
| 58 | 0.0 |
| 59 | 470654.9 |
| 60 | 24240.0 |
| | 0.0 |

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| | |
|----|----------|
| 1 | |
| 2 | 0.0 |
| 3 | 15680.3 |
| 4 | 0.0 |
| 5 | 0.0 |
| 6 | 0.0 |
| 7 | 0.0 |
| 8 | 5050.0 |
| 9 | 257424.8 |
| 10 | 211609.1 |
| 11 | 0.0 |
| 12 | 16816.5 |
| 13 | 64864.2 |
| 14 | 0.0 |
| 15 | 0.0 |
| 16 | 0.0 |
| 17 | 0.0 |
| 18 | 0.0 |
| 19 | 30300.0 |
| 20 | 0.0 |
| 21 | 0.0 |
| 22 | 11586.7 |
| 23 | 0.0 |
| 24 | 0.0 |
| 25 | 729868.4 |
| 26 | 0.0 |
| 27 | 0.0 |
| 28 | 0.0 |
| 29 | 0.0 |
| 30 | 0.0 |
| 31 | 0.0 |
| 32 | 0.0 |
| 33 | 348335.0 |
| 34 | 0.0 |
| 35 | 5000.0 |
| 36 | 0.0 |
| 37 | 23000.0 |
| 38 | 500.0 |
| 39 | 27000.0 |
| 40 | 0.0 |
| 41 | 0.0 |
| 42 | 3884.0 |
| 43 | 0.0 |
| 44 | 0.0 |
| 45 | 0.0 |
| 46 | 0.0 |
| 47 | 10000.0 |
| 48 | 24766.0 |
| 49 | 12706.0 |
| 50 | 16784.0 |
| 51 | 3000.0 |
| 52 | 0.0 |
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| 60 | 0.0 |

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Web Supplement 9. Donors - payments missing from industry data (breakdown for all years)

| Year | Drug company name | Number of payments | Value of payments (2016 £) |
|-----------|--------------------------|--------------------|----------------------------|
| 2012-2016 | RB | 4 | 144270.0 |
| | Genzyme | 52 | 1225894.6 |
| | Sigma Tau Rare Diseases | 8 | 53676.1 |
| | Veriton | 4 | 0.0 |
| | Sanofi Pasteur MSD | 2 | 20989.1 |
| | Fresenius Medical Care | 3 | 15940.6 |
| | Dermal | 13 | 0.0 |
| | Pharma Mar | 2 | 6312.5 |
| | ApoPharma | 5 | 76194.8 |
| | Amdipharm | 4 | 34433.3 |
| | Orphan Europe | 3 | 1028.5 |
| | Gedeon Richter | 2 | 0.0 |
| | PTC | 6 | 0.0 |
| | IQVIA | 1 | 0.0 |
| | Britannia | 4 | 3884.0 |
| | Bausch and Lomb | 4 | 22627.3 |
| | Syner-Med | 3 | 0.0 |
| | Mitsubishi Tanabe Pharma | 1 | 5070.3 |
| | Alliance | 1 | 0.0 |
| | ALK-Abello | 2 | 0.0 |
| Thea | 1 | 0.0 | |
| Diurnal | 1 | 0.0 | |
| Jazz | 1 | 0.0 | |
| Mylan | 1 | 0.0 | |

Web Supplement 10. Donors - summary of payments missing from patient**Year Number of companies missing from patient organi**

| | |
|-------------|----------|
| 2012 | 5 |
| 2013 | 3 |
| 2014 | 7 |
| 2015 | 5 |
| 2016 | 4 |

Total missing - calculate **N/A****Total missing - calculate** **3**

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organisation data

Companies missing from patient organisation data as a share of companies in p

8.9%
4.6%
10.8%
7.1%
6.2%

N/A
3.6%

For peer review only

Number of payments missing from patient organ

| | |
|-----------|-------------|
| 14 | 4.8% |
| 6 | 1.8% |
| 17 | 4.9% |
| 20 | 5.5% |
| 10 | 3.0% |
| 67 | 4.0% |
| 9 | 0.5% |

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Value of payments missing from patient organi: Value of payments missing from patien

| | |
|------------------|-------------|
| 113,328.0 | 3.3% |
| 68,397.8 | 1.5% |
| 138,893.5 | 2.6% |
| 52,758.7 | 1.1% |
| 20,649.1 | 0.1% |
| 394,027.2 | 1.2% |
| 92,208.2 | 0.3% |

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Web Supplement 11. Donors - payments missing from patient organisation data (yearly breakdown)

| Year | Drug company name | Number of payments | Value of payments (2016 £) |
|------|--------------------------|--------------------|----------------------------|
| 2012 | A. Menarini | 2 | 26302.1 |
| | Consilient Health | 2 | 21041.7 |
| | Daiichi Sankyo | 2 | 16833.3 |
| | Meda | 4 | 30589.3 |
| | Servier Laboratories | 4 | 18561.6 |
| 2013 | Consilient Health | 1 | 10285.1 |
| | HRA Pharma | 3 | 46797.4 |
| | Servier Laboratories | 2 | 11315.4 |
| | A. Menarini | 1 | 7605.4 |
| | Almirall | 3 | 47559.2 |
| 2014 | Chugai | 2 | 811.2 |
| | Consilient Health | 1 | 10140.6 |
| | Grünenthal | 3 | 12939.4 |
| | Lundbeck | 5 | 50702.8 |
| | Servier Laboratories | 2 | 9134.9 |
| 2015 | Almirall | 3 | 12538.1 |
| | Chugai | 2 | 15409.9 |
| | Flynn Pharma | 5 | 13700.7 |
| | Rosemont Pharmaceuticals | 7 | 0.0 |
| | Stirling Anglian | 3 | 11110.0 |
| 2016 | Almirall | 3 | 2871.6 |
| | Chugai | 3 | 2612.5 |
| | Flynn Pharma | 3 | 5165.0 |
| | Orion Pharma | 1 | 10000.0 |

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Web Supplement 12. Donors - payments missing from patient organisation data (all years)

| Year | Drug company name | Number of payments | Value of payments (2016 £) |
|-----------|-------------------|--------------------|----------------------------|
| 2012-2016 | A. Menarini | 3 | 33907.5 |
| | Consilient Health | 4 | 41467.4 |
| | Daiichi Sankyo | 2 | 16833.3 |

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Web Supplement 13. Recipients - summary of payments missing from patient organisation

Year Number of patient organisations missing from patient organisation

| | |
|-------------|-----|
| 2012 | 116 |
| 2013 | 123 |
| 2014 | 131 |
| 2015 | 141 |
| 2016 | 143 |

Total missing - calculated annually N/A**Total missing - calculated for all years** 225

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2 **data**

3 **Patient organisations missing from patient organisation data as a share of all pa**
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6 112.6%

7 120.6%

8 112.9%

9 111.9%

10 122.2%

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13 **N/A**

14 **112.5%**
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Number of payments missing from patient organ **Number of payments missing from patient organi**

| | |
|-------------|---------------|
| 399 | 137.1% |
| 369 | 113.2% |
| 411 | 118.8% |
| 462 | 128.0% |
| 533 | 158.2% |
| 2174 | 130.9% |
| 1472 | 88.6% |

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3 **Value of payments missing from patient organi: Value of payments missing from patien**
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6 3,659,293.41 105.8%
7 2,340,576.29 53.0%
8 4,427,502.34 83.5%
9 6,591,354.62 136.6%
10 4,871,241.58 32.4%
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14 **21,889,968.23 66.3%**
15 **14,023,475.41 42.4%**
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t organisation data as share of the value of payments in patient organisation data

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Web Supplement
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For peer review only

Table 14. Recipients - payments missing from patient organisation data (yearly breakdown)**Patient organisation name**

Action on Pain
Action on Pre-Eclampsia
African-Caribbean Leukaemia Trust
Age Related Diseases and Health Trust
Allergy Research Foundation
Alzheimer Scotland
Alzheimers Dementia Support
Anaphylaxis Campaign
Anticoagulation UK
Arrhythmia Alliance
Arthritis and Musculoskeletal Alliance
Atrial Fibrillation Association
Beating Bowel Cancer
Bipolar Scotland
Bipolar UK
Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
Bladder Health UK
Blood Pressure UK
Bluebell Foundation
Brain Charity
Breakthrough Breast Cancer (current name Breast Cancer Now, following merger with Breast Cancer Campaign)
Breast Cancer Campaign (current name Breast Cancer Now, following merger with Breakthrough Breast Cancer)
British Dupuytren's Society
British Heart Foundation
British Obesity Society
Brook
Cancer 52
Cancer Focus Northern Ireland
Cancer Research UK
Child Growth Foundation
Children with Cancer UK
Children's Heart Unit Fund
Children's HIV Association
Chinese National Healthy Living Centre
Cleft Lip and Palate Association
Coping with Cancer in Leicestershire and Rutland
Core Charity
Crohn's in Childhood Research Association
Cure Parkinson's Trust
Cystic Fibrosis Trust
Deaf Education through Listening and Talking
Diabetes Research and Wellness Foundation
Diabetes UK
Disabled Living

1
2 Epilepsy Scotland
3 European Parkinson's Disease Association
4 Family Planning Association
5
6 Forum Link
7 Gay Men's Health
8 GIST Support UK
9
10 Group B Strep Support UK
11 Haemophilia Society
12 Health and Social Care Alliance Scotland
13
14 Heartbeat
15 Hereditary Angioedema UK
16 HIV i-Base
17 Hughes Syndrome Foundation
18
19 ICUsteps
20 Independent Cancer Patients' Voice
21 International Alliance of Patients' Organizations
22
23 Karen Clifford Skcin cancer charity
24 Kidney Cancer UK
25 Leicestershire AIDS Support Services
26
27 Macmillan Cancer Support
28 Maggie's Centre
29 Malnutrition and Nutritional Care in the UK
30
31 Marie Curie Cancer Care
32 Medical Foundation for HIV and Sexual Health
33
34 Melanoma UK
35 Mental Health Foundation
36
37 Migraine Action
38 MPN Voice
39 Myeloma UK
40 Myrovlytis Trust
41 National Eczema Society
42
43 National Kidney Federation
44 National Obesity Forum
45 National Osteoporosis Society
46
47 OcuMel UK
48 Organisation for Sickle Cell Anaemia Research and Thalassaemia Support
49
50 Paget's Association
51 Pain Association Scotland
52
53 Pain Concern
54 Pain Relief Foundation
55
56 Pain UK
57 Pancreatic Cancer UK
58 Patients Association
59
60 Pelvic Pain Support Network
Positive East
Prader-Willi Syndrome Association UK

1 Prostate Cancer Research Centre
2 QUIT
3 Rarer Cancers Foundation
4 Raynaud's and Scleroderma Association (current name: Scleroderma and Raynauds UK, following the
5 Richmond Fellowship
6 Roy Castle Lung Cancer Foundation
7 Salamander Trust
8 SANE
9 SeeAbility
10 Service by Emergency Response Volunteers - Suffolk and Cambridgeshire
11 Shift.MS
12 Silver Star
13 Society for Mucopolysaccharide Diseases
14 Somerville Foundation
15 Spinal Injuries Scotland
16 Spinal Muscular Atrophy Support UK
17 Stroke Association
18 Tackle Prostate Cancer
19 Tenovus Cancer Care
20 Thames Valley Positive Support
21 Thrombosis UK
22 Trigeminal Neuralgia Association
23 UK Gout Society
24 UK Primary Immune-deficiency Patient Support
25 Waverley Care
26 World Child Cancer
27 21 and Co
28 Action on Pain
29 Action on Smoking and Health - Scotland
30 ADHD Foundation
31 African-Caribbean Leukaemia Trust
32 African's Getting Involved
33 Alpha-1 Awareness UK
34 Alpha-1 UK Support Group
35 Anaphylaxis Campaign
36 Anticoagulation UK
37 Arrhythmia Alliance
38 Arthritis and Musculoskeletal Alliance
39 Association for Glycogen Storage Disease
40 Association for Multiple Endocrine Neoplasia Disorders
41 Atrial Fibrillation Association
42 Barts and The London Charity
43 Beating Bowel Cancer
44 Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
45 Bladder Health UK
46 Bloodwise

1 Bowel Cancer UK
2 Breakthrough Breast Cancer (current name Breast Cancer Now, following merger with Breast Cancer ()
3 Breast Cancer Haven (The Haven)
4 British Dupuytren's Society
5 British Heart Foundation
6 British Liver Trust
7 British Polio Fellowship
8 Brittle Bone Society
9 Brook
10 Cancer 52
11 Cancer Research UK
12 Cardiac Risk in the Young
13 Cardiomyopathy UK
14 Cleft Lip and Palate Association
15 Coeliac UK
16 Community Cancer Centre
17 Contact a Family
18 Crohn's in Childhood Research Association
19 Cure Parkinson's Trust
20 Cystic Fibrosis Trust
21 David Lewis Centre
22 Dementia UK
23 Diabetes Research and Wellness Foundation
24 Douglas Bader Foundation
25 Epilepsy Connections
26 Epilepsy Scotland
27 Family Planning Association
28 Forum Link
29 Gauchers Association
30 Gay Men's Health
31 Haemophilia Scotland
32 Haemophilia Society
33 Heart UK
34 Hereditary Angioedema UK
35 HIV i-Base
36 ICUsteps
37 Independent Cancer Patients' Voice
38 International Alliance of Patients' Organizations
39 Juvenile Diabetes Research Foundation
40 Kidney Cancer Support Network
41 Kidney Cancer UK
42 Leicestershire AIDS Support Services
43 Life Education Wessex
44 Liver4Life
45 Lupus Europe
46 Macmillan Cancer Support

1
2 Maggie's Centre
3 Marie Curie Cancer Care
4 Melanoma UK
5
6 Men's Health Forum
7 Mesothelioma UK
8 MPN Voice
9
10 Myeloma UK
11 National AIDS Manual
12 National Eczema Society
13
14 National Kidney Federation
15 National Obesity Forum
16 National Osteoporosis Society
17
18 Northern Ireland Chest, Heart and Stroke
19 OcuMel UK
20 Oliver King Foundation
21
22 Orchid
23 Organisation for Sickle Cell Anaemia Research and Thalassaemia Support
24 Ovacome
25
26 Ovarian Cancer Action
27 Pain Association Scotland
28 Pain Concern
29 Pain UK
30
31 Pancreatic Cancer Action
32 Pancreatic Cancer UK
33 Parkinson's UK
34
35 Patients Association
36 PBC Foundation UK
37 Polycystic Kidney Disease Charity
38
39 Positive East
40 Prostate Cancer Support Organisation
41 Prostate Cancer UK (merged with Prostate Action in 2012, retaining its original name)
42
43 Pumping Marvellous Foundation
44 QUIT
45
46 Rarer Cancers Foundation
47 Restless Leg Syndrome UK
48 Ronald McDonald House Charities
49 Roy Castle Lung Cancer Foundation
50
51 Royal Free Charity
52 SANE
53
54 Sarcoma UK
55 Scoliosis Association UK
56 Scotland Patients Association
57 Scottish Epilepsy Initiative
58 Self Help Services
59
60 Shift.MS
Silver Star

1 South Asian Health Foundation
2 SUDEP Action
3 Target Ovarian Cancer
4 Tenovus Cancer Care
5 Thrombosis UK
6 Transplant Links
7 Trigeminal Neuralgia Association
8 UK Primary Immune-deficiency Patient Support
9 UK Sepsis Trust
10 Waverley Care
11 World Child Cancer
12 AADC Research Trust
13 Action Duchenne
14 Action for Pulmonary Fibrosis
15 Action on Pain
16 Action on Smoking and Health - Wales
17 Actionplus Foundation
18 Addaction
19 Addenbrooks Charitable Trust
20 African Health Policy Network
21 African-Caribbean Leukaemia Trust
22 Alcohol Concern
23 Alpha-1 UK Support Group
24 Anaphylaxis Campaign
25 Anticoagulation UK
26 Arrhythmia Alliance
27 Arthritis and Musculoskeletal Alliance
28 Arthritis Research UK
29 Association for Glycogen Storage Disease
30 Asthma and Allergy Foundation
31 Asthma Relief
32 Atrial Fibrillation Association
33 Basil Skyers Myeloma Foundation
34 Beating Bowel Cancer
35 Behcets Syndrome Society
36 Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
37 Bloodwise
38 Bone Cancer Research Trust
39 Brain Tumor Charity
40 Breast Cancer Campaign (current name Breast Cancer Now, following merger with Breakthrough Brea
41 Breast Cancer Haven (The Haven)
42 British Dupuytren's Society
43 British Heart Foundation
44 British Liver Trust
45 British Pregnancy Advisory Service
46 British Skin Foundation

1 Brook
2
3 Building for the Future
4
5 Cancer 52
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7 Cancer Focus Northern Ireland
8
9 Cancer Research UK
10
11 Catholics for AIDS Prevention and Support
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13 Child Growth Foundation
14
15 Children with Cancer in Malawi
16
17 Chronic Lymphocytic Leukaemia Support Association
18
19 Contact a Family
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21 Core Charity
22
23 Crohn's in Childhood Research Association
24
25 Cure Parkinson's Trust
26
27 Cystic Fibrosis Trust
28
29 Diabetes Research and Wellness Foundation
30
31 Disabled Living
32
33 Edinburgh and Lothian Prostate Cancer Support Group
34
35 Epilepsy Connections
36
37 Epilepsy Scotland
38
39 European Parkinson's Disease Association
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41 Family Planning Association
42
43 Food Chain
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45 FORCE
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47 Forum Link
48
49 Freshwinds
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51 Gay Men's Health
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53 Haemophilia Society
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55 Heart UK
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57 Hepatitis B Positive Trust
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59 HIV i-Base
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Independent Cancer Patients' Voice
Juvenile Diabetes Research Foundation
Karen Clifford Skcin cancer charity
Kidney Cancer Support Network
Kidney Cancer UK
Leukaemia CARE
Liver4Life
Make A Wish Foundation
Melanoma UK
Mental Health Foundation
Mesothelioma UK
Migraine Action
MPN Voice
Multi Organ Transplant Support
National AIDS Manual
National Association for Pre-Menstrual Syndrome

1 National Eczema Society
2 National Kidney Federation
3 National Osteoporosis Society
4 Niemann-Pick UK
5 North of England Bone Marrow and Thalassaemia Association
6 Northern Ireland Rare Disease Partnership
7 Orchid
8 Ovacome
9 Ovarian Cancer Action
10 Paget's Association
11 Pain Concern
12 Pain UK
13 Pancreatic Cancer UK
14 Parkinson's UK
15 Patients Association
16 PBC Foundation UK
17 Polycystic Kidney Disease Charity
18 Positive East
19 Prostate Cancer Support Organisation
20 Prostate Cancer UK (merged with Prostate Action in 2012, retaining its original name)
21 Prostate Cymru
22 Rainbow Centre for Conductive Education
23 Rapid Effective Assistance For Children With Potentially Terminal Illness
24 Rarer Cancers Foundation
25 Raynaud's and Scleroderma Association (current name: Scleroderma and Raynauds UK, following the
26 Release
27 Restless Leg Syndrome UK
28 Revive Multiple Sclerosis Support
29 Roy Castle Lung Cancer Foundation
30 Royal Marsden Cancer Charity
31 Royal National Institute of Blind People
32 SANE
33 Sarcoma UK
34 Scleroderma Society (current name: Scleroderma and Raynauds UK, following the merger of Raynaud
35 Scottish Drugs Forum
36 Scottish Epilepsy Initiative
37 Silver Star
38 Skin Care Cymru
39 Sophia Forum
40 St Thomas Lupus Trust
41 Stroke Association
42 SUDEP Action
43 Tackle Prostate Cancer
44 Transplant Links
45 UK Chronic Lymphocytic Leukaemia Forum
46 UK Gout Society

- 1 UK Primary Immune-deficiency Patient Support
- 2 Walk the Walk Worldwide
- 3 Waverley Care
- 4 World Child Cancer
- 5 Action Duchenne
- 6 Action on Pain
- 7 Addaction
- 8 ADHD Foundation
- 9 African Health Policy Network
- 10 Age UK
- 11 aHUS UK
- 12 Alcohol Concern
- 13 Alpha-1 UK Support Group
- 14 Anaphylaxis Campaign
- 15 Angelman Syndrome Support Education Research Trust
- 16 Anticoagulation UK
- 17 Anxiety UK
- 18 Aplastic Anaemia Trust
- 19 Arrhythmia Alliance
- 20 Arthritis and Musculoskeletal Alliance
- 21 Association for Glycogen Storage Disease
- 22 Atrial Fibrillation Association
- 23 BackCare
- 24 Basil Skyers Myeloma Foundation
- 25 Beat Parkinson's
- 26 Beating Bowel Cancer
- 27 Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
- 28 Bloodwise
- 29 Bluebell Foundation
- 30 Body and Soul
- 31 Bone Cancer Research Trust
- 32 Breast Cancer Campaign (current name Breast Cancer Now, following merger with Breakthrough Breast Cancer)
- 33 Breast Cancer Haven (The Haven)
- 34 Breast Cancer Now (created after the merger of Breast Cancer Campaign and Breakthrough Breast Cancer)
- 35 British Dupuytren's Society
- 36 British Heart Foundation
- 37 British Liver Trust
- 38 British Skin Foundation
- 39 Brook
- 40 Cambridge Rare Disease Network
- 41 Cancer 52
- 42 Cancer Focus Northern Ireland
- 43 Cancer Research UK
- 44 Candlelighters
- 45 Children with Cancer UK
- 46 Children's Liver Disease Foundation

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2 Chronic Lymphocytic Leukaemia Support Association
3 CLIC Sargent Cancer Care For Children
4 Contact a Family
5 Cure Parkinson's Trust
6 Cystic Fibrosis Trust
7 Delete Blood Cancer
8
9 Diabetes UK
10
11 Diabetics with Eating Disorders
12 Diamond Blackfan Anaemia UK
13 Douglas Bader Foundation
14 Encephalitis Society
15 Food Chain
16 Forum Link
17 Freshwinds
18 Friends of FOP
19 Gauchers Association
20 Gay Men's Health
21 Haemophilia Scotland
22 Haemophilia Society
23 Haemophilia Wales
24 Hidradenitis Suppurativa Trust
25 HIV i-Base
26 Independent Cancer Patients' Voice
27 Input Diabetes
28 International Chronic Myeloid Leukemia Foundation
29 Karen Clifford Skcin cancer charity
30 Kidney Cancer Support Network
31 Kidney Cancer UK
32 Kidney Care UK
33 LATCH Welsh Children's Cancer Charity
34 Leeds Teaching Hospital Charitable Foundation
35 Little Hearts Matter
36 Liver4Life
37 Lullaby Trust
38 Lupus Europe
39 Lupus UK
40 Macular Society
41 Maggie's Centre
42 MAMA Academy
43 Melanoma UK
44 Mental Health Foundation
45 Mesothelioma UK
46 Movember Foundation
47 Multiple Births Foundation
48 Myasthenia Gravis Association
49 NARA - The Breathing Charity
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- 1
- 2 National AIDS Manual
- 3 National Eczema Society
- 4 National Kidney Federation
- 5 National Osteoporosis Society
- 6 NMO Research Foundation
- 7 North of England Bone Marrow and Thalassaemia Association
- 8 Older People's Advocacy Alliance
- 9 Ovacome
- 10 Pancreatic Cancer UK
- 11 Patients Association
- 12 Patients On Intravenous and Nasogastric Nutrition Therapy
- 13 Pelvic Pain Support Network
- 14 Portsmouth Down Syndrome Association
- 15 Positive Action
- 16 Progressive Supranuclear Palsy Association
- 17 Prostate Cancer UK (merged with Prostate Action in 2012, retaining its original name)
- 18 QUIT
- 19 Rainbow Trust Children's Charity
- 20 Rapid Effective Assistance For Children With Potentially Terminal Illness
- 21 Rarer Cancers Foundation
- 22 Raynaud's and Scleroderma Association (current name: Scleroderma and Raynauds UK, following the
- 23 Restless Leg Syndrome UK
- 24 Rethink Mental Illness
- 25 River House Trust
- 26 Roy Castle Lung Cancer Foundation
- 27 Royal Free Charity
- 28 Royal National Institute of Blind People
- 29 Salamander Trust
- 30 SANE
- 31 Scleroderma Society (current name: Scleroderma and Raynauds UK, following the merger of Raynaud
- 32 Scottish Kidney Federation
- 33 Sense
- 34 Silver Star
- 35 Skin Care Cymru
- 36 Sophia Forum
- 37 Spectra
- 38 Spinal Injuries Association
- 39 St Thomas Lupus Trust
- 40 Steps
- 41 Stroke Association
- 42 Tackle Prostate Cancer
- 43 TB Alert
- 44 Team Margot
- 45 Teenage Cancer Trust
- 46 Tenovus Cancer Care
- 47 Thrombosis UK

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2 Transverse Myelitis Society
3 Tree of Hope
4 UK Primary Immune-deficiency Patient Support
5 UK Thalassaemia Society
6 Waverley Care
7 World Child Cancer
8
9 York Air Ambulance
10
11 Action Bladder Cancer UK
12 Action Duchenne
13
14 Action on Smoking and Health - Wales
15 Actionplus Foundation
16 Addaction
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18 ADHD Foundation
19 African-Caribbean Leukaemia Trust
20 ALD Life
21 Allergy UK
22
23 Alpha-1 UK Support Group
24 Ankylosing Spondylitis International Federation
25
26 Anthony Nolan
27 Anticoagulation UK
28 Arrhythmia Alliance
29
30 Arthritis and Musculoskeletal Alliance
31 Asyabi UK
32 Atrial Fibrillation Association
33
34 Back on Track
35 BackCare
36 Basil Skyers Myeloma Foundation
37 Beating Bowel Cancer
38
39 Birdshot Uveitis Society
40 Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
41 Body and Soul
42
43 Brain Tumour Research
44 Breast Cancer Haven (The Haven)
45
46 British Dupuytren's Society
47 British Liver Trust
48
49 British Skin Foundation
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51 Brook
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53 Cambridge Rare Disease Network
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55 Cancer 52
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57 Cancer Focus Northern Ireland
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59 Cancer Research UK
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61 Cardiac Risk in the Young
62
63 Cardiomyopathy UK
64
65 Charlie Waller Memorial Trust
66
67 Child Growth Foundation
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69 Children's Liver Disease Foundation

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2 Chronic Lymphocytic Leukaemia Support Association
3 CLIC Sargent Cancer Care For Children
4 Coppafeel!
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6 Crohn's in Childhood Research Association
7 Cure and Action for Tay-Sachs
8 Cure Parkinson's Trust
9
10 Cystic Fibrosis Trust
11 Delete Blood Cancer
12 Diabetes UK
13
14 Diabetics with Eating Disorders
15 Different Strokes
16 Disabled Living
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18 Encephalitis Society
19 Epilepsy Action
20 Epilepsy Scotland
21
22 Family Planning Association
23 Foundation for Liver Research
24 GIST Support UK
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26 Guillain Barre and associated inflammatory neuropathies
27 Haemophilia Scotland
28 Haemophilia Society
29 Haemophilia Wales
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31 Hafal
32 Headway
33 Heart UK
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35 HIV i-Base
36 HIV Scotland
37
38 Imperial College Healthcare Charity
39 Independent Cancer Patients' Voice
40 Juvenile Diabetes Research Foundation
41 KAITY
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43 Karen Clifford Skcin cancer charity
44 Kidney Cancer Support Network
45 Kidney Cancer UK
46 Kidney Care UK
47
48 Liver4Life
49 Lupus Europe
50
51 Macmillan Cancer Support
52 Make A Wish Foundation
53 Marie Curie Cancer Care
54
55 Martin Fisher Foundation
56 MDS UK Support Group
57
58 Melanoma Focus
59 Melanoma Fund
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Melanoma UK
Mesothelioma UK

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2 Migraine Action
3 Motor Neurone Disease Association
4 MPN Voice
5 Multiple Sclerosis UK
6 Muscular Dystrophy UK
7 National Attention Deficit Disorder Information and Support Service
8
9 National Cancer Research Institute
10
11 National Childbirth Trust
12 National Eczema Society
13 National Kidney Federation
14 National Osteoporosis Society
15 National Rheumatoid Arthritis Society
16 NMO Research Foundation
17 Northern Ireland Rare Disease Partnership
18 Olive Tree Cancer Support Centre - Crawley
19 Ovacome
20 Ovarian Cancer Action
21 Paget's Association
22 Pain Concern
23 Pancreatic Cancer Action
24 Parkinson's UK
25 Patients Association
26 Patients On Intravenous and Nasogastric Nutrition Therapy
27 Paula Carr Diabetes Trust
28 Pelican Cancer Foundation
29 Pink Ribbon Foundation – Breast Cancer Charity
30 Polycystic Kidney Disease Charity
31 Progressive Supranuclear Palsy Association
32 QUIT
33 Rarer Cancers Foundation
34 Restless Leg Syndrome UK
35 Roy Castle Lung Cancer Foundation
36 Royal National Institute of Blind People
37 Samson Centre for MS
38 SANE
39 Sarcoma UK
40 Save Babies Through Screening Foundation UK
41 Scleroderma and Raynauds UK (established following the merger of Raynaud's and Scleroderma Asso
42 Scottish Network Children with Arthrities
43 Sexual Advice Association
44 Short Bowel Survivor and Friends
45 Skin Care Cymru
46 Somerville Foundation
47 Sussex Beacon
48 Tackle Prostate Cancer
49 Teenage Cancer Trust
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- 2 Tenovus Cancer Care
- 3 Thames Valley Positive Support
- 4 Thrombosis UK
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- 6 Tuberous Sclerosis Association
- 7 Visionary
- 8 Waldenstroms Macroglobulinaemia UK
- 9
- 10 Waverley Care
- 11 WellChild
- 12 Willow Foundation
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- 14 World Cancer Research Fund
- 15 World Child Cancer
- 16 Young Epilepsy
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Number of payments Value of payments (2016 £)

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| 6 | 1 | 10520.8 |
| 7 | 1 | 15781.3 |
| 8 | 2 | 39258.9 |
| 9 | | |
| 10 | 2 | 21041.7 |
| 11 | 2 | 563.6 |
| 12 | 1 | 1057.3 |
| 13 | | |
| 14 | 1 | 15860.2 |
| 15 | 12 | 20260.5 |
| 16 | 6 | 7381.0 |
| 17 | | |
| 18 | 5 | 37832.9 |
| 19 | 36 | 227017.3 |
| 20 | 5 | 36010.8 |
| 21 | | |
| 22 | 3 | 3193.8 |
| 23 | 3 | 4145.2 |
| 24 | 13 | 415672.2 |
| 25 | | |
| 26 | 7 | 6165.9 |
| 27 | 1 | 10520.8 |
| 28 | 1 | 473.4 |
| 29 | | |
| 30 | 1 | 981.5 |
| 31 | 2 | 5298.0 |
| 32 | 1 | 6312.5 |
| 33 | | |
| 34 | 2 | 599.7 |
| 35 | 1 | 117.8 |
| 36 | 1 | 420.8 |
| 37 | | |
| 38 | 4 | 33929.7 |
| 39 | 5 | 33140.6 |
| 40 | 3 | 5681.3 |
| 41 | | |
| 42 | 10 | 660846.1 |
| 43 | 1 | 1578.1 |
| 44 | 1 | 473.4 |
| 45 | 1 | 736.5 |
| 46 | | |
| 47 | 1 | 7890.6 |
| 48 | 1 | 252.5 |
| 49 | 1 | 58.9 |
| 50 | | |
| 51 | 1 | 4187.3 |
| 52 | 1 | 8416.7 |
| 53 | 3 | 12625.0 |
| 54 | | |
| 55 | 1 | 254.6 |
| 56 | 2 | 12650.6 |
| 57 | 1 | 526.0 |
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| 59 | 1 | 2104.2 |
| 60 | 29 | 315722.5 |
| | 1 | 5260.4 |

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| 1 | | |
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| 4 | 3 | 7680.2 |
| 5 | 2 | 747.0 |
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| 8 | 1 | 153.6 |
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| 10 | 1 | 37.6 |
| 11 | 1 | 757.5 |
| 12 | 3 | 24923.9 |
| 13 | 4 | 16970.1 |
| 14 | 1 | 2104.2 |
| 15 | 1 | 2099.5 |
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| 17 | 3 | 122044.1 |
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| 20 | 2 | 925.8 |
| 21 | 5 | 19768.6 |
| 22 | 1 | 157.8 |
| 23 | 1 | 883.8 |
| 24 | 1 | 241.4 |
| 25 | 1 | 5260.4 |
| 26 | 2 | 21041.7 |
| 27 | 2 | 79095.6 |
| 28 | 2 | 25776.0 |
| 29 | 2 | 18170.9 |
| 30 | 7 | 215976.6 |
| 31 | 1 | 1420.3 |
| 32 | 9 | 20541.9 |
| 33 | 8 | 144188.0 |
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| 35 | 3 | 13082.8 |
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| 37 | 1 | 2104.2 |
| 38 | 1 | 2104.2 |
| 39 | 4 | 3000.9 |
| 40 | 4 | 6689.5 |
| 41 | 1 | 631.3 |
| 42 | 4 | 16916.6 |
| 43 | 1 | 8416.7 |
| 44 | 10 | 66089.5 |
| 45 | 3 | 1188.0 |
| 46 | 1 | 16496.7 |
| 47 | 1 | 473.4 |

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| 1 | | |
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| 3 | 7 | 19502.5 |
| 4 | 16 | 134019.4 |
| 5 | 5 | 5946.4 |
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| 7 | 11 | 136368.8 |
| 8 | 1 | 417.7 |
| 9 | 1 | 1052.1 |
| 10 | 1 | 473.4 |
| 11 | 1 | 210.4 |
| 12 | 1 | 2865.9 |
| 13 | 4 | 40505.2 |
| 14 | 14 | 161724.0 |
| 15 | 2 | 6327.7 |
| 16 | 1 | 1052.1 |
| 17 | 1 | 26302.1 |
| 18 | 3 | 4771.9 |
| 19 | 1 | 5260.4 |
| 20 | 1 | 45554.2 |
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| 22 | 5 | 19805.5 |
| 23 | 2 | 4208.3 |
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| 27 | 2 | 16096.9 |
| 28 | 1 | 1028.5 |
| 29 | 6 | 5139.5 |
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| 31 | 1 | 205.7 |
| 32 | 1 | 18513.2 |
| 33 | 1 | 129.6 |
| 34 | 2 | 16456.2 |
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| 39 | 5 | 52570.4 |
| 40 | 1 | 2057.0 |
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| 46 | 3 | 8377.2 |
| 47 | 1 | 236.7 |

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| 1 | | |
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| 5 | 3 | 2611.4 |
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| 7 | 2 | 15633.4 |
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| 12 | 9 | 33791.8 |
| 13 | 1 | 462.8 |
| 14 | 1 | 518.7 |
| 15 | 1 | 62.0 |
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| 17 | 1 | 1028.5 |
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| 22 | 1 | 1892.5 |
| 23 | 1 | 2592.9 |
| 24 | 1 | 2057.0 |
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| 36 | 4 | 16263.9 |
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| 38 | 1 | 3085.5 |
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| 13 | 8 | 22156.9 |
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| 15 | 1 | 1028.5 |
| 16 | 1 | 510.9 |
| 17 | 1 | 3085.5 |
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| 20 | 1 | 10285.1 |
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| 23 | 3 | 6582.5 |
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| 30 | 2 | 579.1 |
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| 37 | 1 | 771.4 |
| 38 | 14 | 124200.5 |
| 39 | 1 | 11321.9 |
| 40 | 1 | 20428.5 |
| 41 | 1 | 1028.5 |
| 42 | 1 | 277.7 |
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| 44 | 1 | 2571.3 |
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| 46 | 3 | 41140.5 |
| 47 | 6 | 48340.1 |

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| 4 | 1 | 0.0 |
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| 7 | 3 | 14399.2 |
| 8 | 1 | 771.4 |
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| 12 | 1 | 0.0 |
| 13 | 1 | 4114.1 |
| 14 | 1 | 4114.1 |
| 15 | 2 | 20914.8 |
| 16 | 1 | 5070.3 |
| 17 | 1 | 5070.3 |
| 18 | 2 | 3042.2 |
| 19 | 1 | 595.8 |
| 20 | 2 | 4056.2 |
| 21 | 1 | 2028.1 |
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| 23 | 1 | 2940.8 |
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| 26 | 1 | 3042.2 |
| 27 | 2 | 20854.0 |
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| 31 | 1 | 60843.4 |
| 32 | 1 | 608.4 |
| 33 | 8 | 60166.5 |
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| 35 | 6 | 89084.8 |
| 36 | 9 | 85180.7 |
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| 38 | 3 | 583.1 |
| 39 | 1 | 7098.4 |
| 40 | 1 | 507.0 |
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| 46 | 8 | 133200.9 |
| 47 | 1 | 20281.1 |
| 48 | 6 | 234694.2 |
| 49 | 6 | 234694.2 |
| 50 | 3 | 16934.7 |
| 51 | 2 | 10140.6 |
| 52 | 1 | 12675.7 |
| 53 | 5 | 65913.7 |
| 54 | 5 | 65913.7 |
| 55 | 2 | 12417.3 |
| 56 | 1 | 11465.2 |
| 57 | 2 | 354.9 |
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| 60 | 1 | 507.0 |
| | 3 | 3549.2 |

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| 1 | | |
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| 3 | 1 | 243.4 |
| 4 | 5 | 39041.2 |
| 5 | 7 | 10280.6 |
| 6 | 9 | 425099.6 |
| 7 | 1 | 4089.1 |
| 8 | 1 | 1521.1 |
| 9 | 1 | 20179.7 |
| 10 | 1 | 20281.1 |
| 11 | 1 | 7605.4 |
| 12 | 1 | 8112.4 |
| 13 | 2 | 7098.4 |
| 14 | 2 | 342.6 |
| 15 | 4 | 7250.5 |
| 16 | 1 | 2433.7 |
| 17 | 3 | 17827.1 |
| 18 | 2 | 804.5 |
| 19 | 1 | 2028.1 |
| 20 | 3 | 3442.7 |
| 21 | 2 | 24984.5 |
| 22 | 3 | 22917.7 |
| 23 | 1 | 3042.2 |
| 24 | 1 | 507.0 |
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| 26 | 1 | 3042.2 |
| 27 | 3 | 11734.7 |
| 28 | 15 | 112989.0 |
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| 30 | 1 | 5070.3 |
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| 44 | 1 | 22682.4 |
| 45 | 1 | 6084.3 |
| 46 | 7 | 82397.2 |
| 47 | 1 | 152.1 |

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| 4 | 3 | 77459.8 |
| 5 | 2 | 16267.8 |
| 6 | 3 | 4563.3 |
| 7 | 1 | 2535.1 |
| 8 | 1 | 248.6 |
| 9 | 1 | 10951.8 |
| 10 | 1 | 19267.1 |
| 11 | 1 | 15210.8 |
| 12 | 1 | 3042.2 |
| 13 | 3 | 6601.5 |
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| 15 | 3 | 6135.0 |
| 16 | 9 | 69674.0 |
| 17 | 2 | 608.4 |
| 18 | 1 | 15210.8 |
| 19 | 1 | 4563.3 |
| 20 | 1 | 461.8 |
| 21 | 5 | 26839.5 |
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| 24 | 1 | 2738.0 |
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| 27 | 1 | 10063.5 |
| 28 | 2 | 3338.3 |
| 29 | 1 | 40562.2 |
| 30 | 13 | 179410.6 |
| 31 | 1 | 354.9 |
| 32 | 9 | 282414.7 |
| 33 | 2 | 26365.5 |
| 34 | 1 | 1014.1 |
| 35 | 1 | 671.8 |
| 36 | 2 | 4056.2 |
| 37 | 1 | 76054.2 |
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| 39 | 2 | 1014.1 |
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| 41 | 2 | 835.0 |
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| 44 | 4 | 9011.9 |
| 45 | 1 | 760.5 |
| 46 | 1 | 4056.2 |
| 47 | 2 | 27886.5 |

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| 3 | 1 | 405.6 |
| 4 | 3 | 19058.2 |
| 5 | 3 | 163600.7 |
| 6 | 7 | 32262.1 |
| 7 | 5 | 1262.5 |
| 8 | 1 | 189819.4 |
| 9 | 9 | 16160.0 |
| 10 | 3 | 10327.3 |
| 11 | 4 | 555.5 |
| 12 | 2 | 25250.0 |
| 13 | 1 | 52988.6 |
| 14 | 6 | 60600.0 |
| 15 | 1 | 3030.0 |
| 16 | 4 | 303.0 |
| 17 | 1 | 118527.0 |
| 18 | 18 | 3282.5 |
| 19 | 1 | 1616.0 |
| 20 | 1 | 108324.5 |
| 21 | 10 | 61610.0 |
| 22 | 8 | 18555.7 |
| 23 | 4 | 107478.3 |
| 24 | 14 | 3535.0 |
| 25 | 1 | 18852.7 |
| 26 | 1 | 5050.0 |
| 27 | 1 | 77810.4 |
| 28 | 9 | 1473965.2 |
| 29 | 11 | 40753.5 |
| 30 | 6 | 303.0 |
| 31 | 1 | 57945.7 |
| 32 | 4 | 2020.0 |
| 33 | 1 | 9090.0 |
| 34 | 1 | 19705.1 |
| 35 | 1 | 0.0 |
| 36 | 1 | 31916.0 |
| 37 | 1 | 666.6 |
| 38 | 1 | 17018.5 |
| 39 | 5 | 4155.1 |
| 40 | 1 | 8080.0 |
| 41 | 1 | 1574.6 |
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| 44 | 2 | 662211.6 |
| 45 | 14 | 0.0 |
| 46 | 1 | 151.5 |
| 47 | 1 | 1010.0 |
| 48 | 1 | |
| 49 | 1 | |
| 50 | 1 | |
| 51 | 1 | |
| 52 | 1 | |
| 53 | 1 | |
| 54 | 1 | |
| 55 | 1 | |
| 56 | 1 | |
| 57 | 1 | |
| 58 | 1 | |
| 59 | 1 | |
| 60 | 1 | |

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| 1 | | |
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| 4 | 1 | 5050.0 |
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| 6 | 1 | 9595.0 |
| 7 | 2 | 14402.6 |
| 8 | 2 | 899692.9 |
| 9 | 44 | 1347.3 |
| 10 | 3 | 15150.0 |
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| 12 | 1 | 505.0 |
| 13 | 1 | 5050.0 |
| 14 | 1 | 13907.7 |
| 15 | 1 | 8888.0 |
| 16 | 1 | 0.0 |
| 17 | 1 | 19493.0 |
| 18 | 3 | 505.0 |
| 19 | 1 | 13847.3 |
| 20 | 8 | 190024.6 |
| 21 | 14 | 5972.6 |
| 22 | 5 | 6019.6 |
| 23 | 2 | 8080.0 |
| 24 | 1 | 4545.0 |
| 25 | 2 | 30322.2 |
| 26 | 1 | 34105.2 |
| 27 | 3 | 27270.0 |
| 28 | 3 | 20200.0 |
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| 31 | 1 | 1010.0 |
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| 33 | 1 | 252.5 |
| 34 | 1 | 131184.9 |
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| 36 | 1 | 25668.1 |
| 37 | 1 | 707.0 |
| 38 | 1 | 15.2 |
| 39 | 1 | 445.9 |
| 40 | 1 | 202.0 |
| 41 | 1 | 124798.6 |
| 42 | 6 | 1212.0 |
| 43 | 1 | 10100.0 |
| 44 | 1 | 1010.0 |
| 45 | 1 | 505.0 |
| 46 | 1 | 2020.0 |
| 47 | 1 | 0.0 |
| 48 | 1 | |
| 49 | 1 | |
| 50 | 1 | |
| 51 | 1 | |
| 52 | 1 | |
| 53 | 1 | |
| 54 | 1 | |
| 55 | 1 | |
| 56 | 1 | |
| 57 | 1 | |
| 58 | 1 | |
| 59 | 1 | |
| 60 | 1 | |

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| 1 | | |
| 2 | 7 | 47908.3 |
| 3 | 1 | 202.0 |
| 4 | 5 | 61027.2 |
| 5 | 8 | 95647.0 |
| 6 | 1 | 5050.0 |
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| 8 | 2 | 30300.0 |
| 9 | 2 | 32572.5 |
| 10 | 4 | 122715.0 |
| 11 | 9 | 64371.2 |
| 12 | 1 | 1520.2 |
| 13 | 1 | 1466.7 |
| 14 | 1 | 151.5 |
| 15 | 1 | 0.0 |
| 16 | 1 | 151.5 |
| 17 | 2 | 5302.5 |
| 18 | 2 | 32115.0 |
| 19 | 1 | 1010.0 |
| 20 | 1 | 2462.4 |
| 21 | 10 | 126755.0 |
| 22 | 3 | 20200.0 |
| 23 | 1 | 3030.0 |
| 24 | 1 | 757.5 |
| 25 | 1 | 252.5 |
| 26 | 14 | 164788.4 |
| 27 | 1 | 505.0 |
| 28 | 7 | 230060.8 |
| 29 | 1 | 303.0 |
| 30 | 2 | 15840.8 |
| 31 | 2 | 2473.5 |
| 32 | 1 | 505.0 |
| 33 | 1 | 151.5 |
| 34 | 1 | 10100.0 |
| 35 | 4 | 18060.7 |
| 36 | 1 | 5050.0 |
| 37 | 1 | 1010.0 |
| 38 | 1 | 252.5 |
| 39 | 2 | 62115.0 |
| 40 | 1 | 151.5 |
| 41 | 9 | 47571.0 |
| 42 | 5 | 83197.3 |
| 43 | 2 | 27401.3 |
| 44 | 1 | 5050.0 |
| 45 | 1 | 1010.0 |
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| 47 | 2 | 62115.0 |
| 48 | 1 | 151.5 |
| 49 | 9 | 47571.0 |
| 50 | 5 | 83197.3 |
| 51 | 2 | 27401.3 |
| 52 | 1 | 5050.0 |
| 53 | 1 | 1010.0 |
| 54 | 4 | 3838.0 |
| 55 | 4 | 70809.1 |
| 56 | 4 | 70809.1 |
| 57 | 1 | 2525.0 |
| 58 | 2 | 2525.0 |
| 59 | 2 | 2525.0 |
| 60 | 2 | 2525.0 |

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| 1 | | |
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| 3 | 1 | 151.5 |
| 4 | 2 | 20701.0 |
| 5 | 1 | 4040.0 |
| 6 | 1 | 4040.0 |
| 7 | 5 | 15361.1 |
| 8 | 1 | 50499.9 |
| 9 | | |
| 10 | 1 | 0.0 |
| 11 | 1 | 101.0 |
| 12 | 5 | 11772.1 |
| 13 | | |
| 14 | 1 | 5000.0 |
| 15 | 1 | 5000.0 |
| 16 | 2 | 45000.0 |
| 17 | | |
| 18 | 4 | 6620.0 |
| 19 | 1 | 15000.0 |
| 20 | 1 | 262.3 |
| 21 | | |
| 22 | 3 | 10160.5 |
| 23 | 1 | 1200.0 |
| 24 | 6 | 38722.8 |
| 25 | | |
| 26 | 1 | 20000.0 |
| 27 | 18 | 103102.5 |
| 28 | 6 | 46355.0 |
| 29 | | |
| 30 | 5 | 25000.0 |
| 31 | 1 | 1500.0 |
| 32 | 14 | 91536.8 |
| 33 | 1 | 3809.2 |
| 34 | | |
| 35 | 2 | 4000.0 |
| 36 | 2 | 9250.0 |
| 37 | | |
| 38 | 15 | 64682.6 |
| 39 | 1 | 10000.0 |
| 40 | 6 | 125466.9 |
| 41 | | |
| 42 | 2 | 40000.0 |
| 43 | 1 | 262.3 |
| 44 | 1 | 15000.0 |
| 45 | 1 | 9000.0 |
| 46 | | |
| 47 | 8 | 43810.0 |
| 48 | 2 | 2080.2 |
| 49 | | |
| 50 | 1 | 5000.0 |
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| 52 | 7 | 80375.0 |
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| 54 | 1 | 824.2 |
| 55 | 15 | 35685.8 |
| 56 | 6 | 5808.1 |
| 57 | 4 | 1819.2 |
| 58 | | |
| 59 | 1 | 1000.0 |
| 60 | 2 | 5937.2 |
| | 1 | 15000.0 |

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| 3 | 1 | 853.0 |
| 4 | 1 | 10000.0 |
| 5 | 2 | 650.0 |
| 6 | 2 | 120.0 |
| 7 | 3 | 9914.0 |
| 8 | 6 | 250684.0 |
| 9 | 1 | 262.3 |
| 10 | 55 | 972606.1 |
| 11 | 1 | 200.0 |
| 12 | 5 | 10786.9 |
| 13 | 1 | 500.0 |
| 14 | 1 | 262.3 |
| 15 | 1 | 1624.0 |
| 16 | 2 | 1351.0 |
| 17 | 1 | 15000.0 |
| 18 | 1 | 57537.0 |
| 19 | 5 | 35143.0 |
| 20 | 2 | 6400.0 |
| 21 | 2 | 13000.0 |
| 22 | 14 | 158595.7 |
| 23 | 5 | 7748.3 |
| 24 | 1 | 4000.0 |
| 25 | 1 | 150.0 |
| 26 | 15 | 227311.4 |
| 27 | 2 | 11500.0 |
| 28 | 1 | 3000.0 |
| 29 | 1 | 4000.0 |
| 30 | 5 | 15115.4 |
| 31 | 1 | 36000.0 |
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| 33 | 1 | 10000.0 |
| 34 | 4 | 32597.2 |
| 35 | 11 | 38214.9 |
| 36 | 1 | 228.0 |
| 37 | 10 | 57018.2 |
| 38 | 2 | 21101.4 |
| 39 | 14 | 98362.3 |
| 40 | 1 | 257.6 |
| 41 | 1 | 150.0 |
| 42 | 1 | 15000.0 |
| 43 | 3 | 7068.8 |
| 44 | 3 | 46207.0 |
| 45 | 2 | 15000.0 |
| 46 | 8 | 87500.0 |
| 47 | 3 | 3900.0 |

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| 3 | 2 | 280.0 |
| 4 | 2 | 2355.5 |
| 5 | 1 | 603.4 |
| 6 | 1 | 6000.0 |
| 7 | 1 | 45.0 |
| 8 | 1 | 1000.0 |
| 9 | 1 | 9600.0 |
| 10 | 1 | 300.0 |
| 11 | 4 | 48000.0 |
| 12 | 13 | 118394.2 |
| 13 | 15 | 121433.8 |
| 14 | 2 | 1600.0 |
| 15 | 1 | 1500.0 |
| 16 | 1 | 3400.0 |
| 17 | 1 | 15000.0 |
| 18 | 1 | 10000.0 |
| 19 | 1 | 7405.6 |
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| 21 | 1 | 1250.0 |
| 22 | 4 | 1984.0 |
| 23 | 11 | 83416.0 |
| 24 | 4 | 28328.7 |
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| 26 | 1 | 8500.0 |
| 27 | 1 | 10000.0 |
| 28 | 1 | 44000.0 |
| 29 | 2 | 412.3 |
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| 31 | 9 | 105050.0 |
| 32 | 1 | 4000.0 |
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| 34 | 9 | 178153.0 |
| 35 | 1 | 4500.0 |
| 36 | 1 | 20000.0 |
| 37 | 1 | 3000.0 |
| 38 | 1 | 981.0 |
| 39 | 1 | 2000.0 |
| 40 | 3 | 1139.3 |
| 41 | 1 | 30000.0 |
| 42 | 1 | 224.0 |
| 43 | 2 | 850.0 |
| 44 | 1 | 1000.0 |
| 45 | 1 | 1000.0 |
| 46 | 3 | 51000.0 |
| 47 | 2 | 2538.0 |

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| 5 | 1 | 23754.0 |
| 6 | 2 | 15000.0 |
| 7 | 3 | 9851.0 |
| 8 | 7 | 56002.3 |
| 9 | 2 | 262000.0 |
| 10 | 1 | 257.6 |
| 11 | 1 | 5000.0 |
| 12 | 3 | 91163.6 |
| 13 | 1 | 18000.0 |
| 14 | | |
| 15 | | |
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For peer review only

Web Supplement 15. Recipients - payments missing from patient organisation data (all years)**Patient organisation name**

21 and Co
AADC Research Trust
Action Bladder Cancer UK
Action Duchenne
Action on Pain
Action on Smoking and Health - Scotland
Actionplus Foundation
Addenbrooks Charitable Trust
African-Caribbean Leukaemia Trust
African's Getting Involved
Age Related Diseases and Health Trust
aHUS UK
ALD Life
Allergy Research Foundation
Alpha-1 Awareness UK
Alpha-1 UK Support Group
Alzheimer Scotland
Alzheimers Dementia Support
Angelman Syndrome Support Education Research Trust
Ankylosing Spondylitis International Federation
Anticoagulation UK
Aplastic Anaemia Trust
Arrhythmia Alliance
Arthritis and Musculoskeletal Alliance
Asthma and Allergy Foundation
Asthma Relief
Asyabi UK
Atrial Fibrillation Association
Back on Track
Barts and The London Charity
Basil Skyers Myeloma Foundation
Beat Parkinson's
Beating Bowel Cancer
Behcets Syndrome Society
Bipolar Scotland
Bipolar UK
Birdshot Uveitis Society
Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
Blood Pressure UK
Bluebell Foundation
Body and Soul
Bone Cancer Research Trust
Brain Charity
Brain Tumor Charity

1 Brain Tumour Research
2 Breast Cancer Campaign (current name Breast Cancer Now, following merger with Breakthrough Brea
3 Breast Cancer Haven (The Haven)
4 British Dupuytren's Society
5 British Heart Foundation
6 British Obesity Society
7 British Polio Fellowship
8 British Skin Foundation
9 Brook
10 Building for the Future
11 Cambridge Rare Disease Network
12 Cancer 52
13 Cancer Focus Northern Ireland
14 Cancer Research UK
15 Candlelighters
16 Cardiac Risk in the Young
17 Cardiomyopathy UK
18 Catholics for AIDS Prevention and Support
19 Charlie Waller Memorial Trust
20 Children with Cancer UK
21 Children's Liver Disease Foundation
22 Children's Heart Unit Fund
23 Chinese National Healthy Living Centre
24 Chronic Lymphocytic Leukaemia Support Association
25 Cleft Lip and Palate Association
26 CLIC Sargent Cancer Care For Children
27 Community Cancer Centre
28 Contact a Family
29 Coping with Cancer in Leicestershire and Rutland
30 Crohn's in Childhood Research Association
31 Cure Parkinson's Trust
32 Cystic Fibrosis Trust
33 David Lewis Centre
34 Deaf Education through Listening and Talking
35 Delete Blood Cancer
36 Dementia UK
37 Diabetes Research and Wellness Foundation
38 Diabetics with Eating Disorders
39 Diamond Blackfan Anaemia UK
40 Different Strokes
41 Douglas Bader Foundation
42 Edinburgh and Lothian Prostate Cancer Support Group
43 Encephalitis Society
44 Epilepsy Connections
45 Epilepsy Scotland
46 FORCE

1 Forum Link
2 Freshwinds
3 Group B Strep Support UK
4 Guillain Barre and associated inflammatory neuropathies
5 Haemophilia Society
6 Haemophilia Wales
7 Hafal
8 Headway
9 Health and Social Care Alliance Scotland
10 Heartbeat
11 Hepatitis B Positive Trust
12 HIV i-Base
13 Hughes Syndrome Foundation
14 ICUsteps
15 Imperial College Healthcare Charity
16 Independent Cancer Patients' Voice
17 Input Diabetes
18 KAITY
19 Karen Clifford Skcin cancer charity
20 Kidney Cancer Support Network
21 Kidney Cancer UK
22 Kidney Care UK
23 LATCH Welsh Children's Cancer Charity
24 Leeds Teaching Hospital Charitable Foundation
25 Leicestershire AIDS Support Services
26 Life Education Wessex
27 Little Hearts Matter
28 Liver4Life
29 Lullaby Trust
30 Lupus Europe
31 Lupus UK
32 Macular Society
33 Maggie's Centre
34 Make A Wish Foundation
35 Malnutrition and Nutritional Care in the UK
36 MAMA Academy
37 Marie Curie Cancer Care
38 Martin Fisher Foundation
39 Melanoma UK
40 Mesothelioma UK
41 Motor Neurone Disease Association
42 Movember Foundation
43 MPN Voice
44 Multi Organ Transplant Support
45 Multiple Births Foundation
46 Multiple Sclerosis UK

1 Myasthenia Gravis Association
2 Myrovlytis Trust
3 NARA - The Breathing Charity
4 National Association for Pre-Menstrual Syndrome
5 National Cancer Research Institute
6 National Eczema Society
7 National Kidney Federation
8 National Obesity Forum
9 National Osteoporosis Society
10 NMO Research Foundation
11 North of England Bone Marrow and Thalassaemia Association
12 Northern Ireland Chest, Heart and Stroke
13 Northern Ireland Rare Disease Partnership
14 OcuMel UK
15 Olive Tree Cancer Support Centre - Crawley
16 Oliver King Foundation
17 Orchid
18 Organisation for Sickle Cell Anaemia Research and Thalassaemia Support
19 Ovacom
20 Paget's Association
21 Pain Association Scotland
22 Pain Concern
23 Pain UK
24 Patients Association
25 Patients On Intravenous and Nasogastric Nutrition Therapy
26 Paula Carr Diabetes Trust
27 Pelican Cancer Foundation
28 Pelvic Pain Support Network
29 Pink Ribbon Foundation – Breast Cancer Charity
30 Polycystic Kidney Disease Charity
31 Portsmouth Down Syndrome Association
32 Positive Action
33 Prader-Willi Syndrome Association UK
34 Progressive Supranuclear Palsy Association
35 Prostate Cancer Research Centre
36 Prostate Cymru
37 QUIT
38 Rainbow Centre for Conductive Education
39 Rainbow Trust Children's Charity
40 Rarer Cancers Foundation
41 Restless Leg Syndrome UK
42 Richmond Fellowship
43 River House Trust
44 Ronald McDonald House Charities
45 Roy Castle Lung Cancer Foundation
46 Royal Marsden Cancer Charity

1 Salamander Trust
2 Samson Centre for MS
3 SANE
4 Scoliosis Association UK
5 Scotland Patients Association
6 Scottish Drugs Forum
7 Scottish Epilepsy Initiative
8 Scottish Kidney Federation
9 Scottish Network Children with Arthrities
10 SeeAbility
11 Self Help Services
12 Sense
13 Service by Emergency Response Volunteers - Suffolk and Cambridgeshire
14 Short Bowel Survivor and Friends
15 Silver Star
16 Skin Care Cymru
17 Somerville Foundation
18 Sophia Forum
19 Spectra
20 Spinal Injuries Association
21 Spinal Injuries Scotland
22 St Thomas Lupus Trust
23 Steps
24 SUDEP Action
25 Sussex Beacon
26 Tackle Prostate Cancer
27 Team Margot
28 Tenovus Cancer Care
29 Thames Valley Positive Support
30 Thrombosis UK
31 Transplant Links
32 Transverse Myelitis Society
33 Tree of Hope
34 Trigeminal Neuralgia Association
35 UK Chronic Lymphocytic Leukaemia Forum
36 UK Gout Society
37 UK Sepsis Trust
38 Walk the Walk Worldwide
39 Waverley Care
40 Willow Foundation
41 World Cancer Research Fund
42 World Child Cancer
43 York Air Ambulance

Number of payments Value of payments (2016 £)

| | | |
|----|-----|-----------|
| 1 | | |
| 2 | | |
| 3 | | |
| 4 | | |
| 5 | 1 | 1028.5 |
| 6 | 1 | 5070.3 |
| 7 | 1 | 101.0 |
| 8 | 12 | 47076.4 |
| 9 | 12 | 13947.1 |
| 10 | 12 | 13947.1 |
| 11 | 1 | 2519.9 |
| 12 | 2 | 7940.8 |
| 13 | 1 | 3042.2 |
| 14 | 1 | 3042.2 |
| 15 | 6 | 70151.6 |
| 16 | 1 | 129.6 |
| 17 | 1 | 129.6 |
| 18 | 2 | 39258.9 |
| 19 | 1 | 25250.0 |
| 20 | 1 | 262.3 |
| 21 | 1 | 262.3 |
| 22 | 2 | 21041.7 |
| 23 | 2 | 16456.2 |
| 24 | 5 | 138585.3 |
| 25 | 2 | 563.6 |
| 26 | 2 | 563.6 |
| 27 | 1 | 1057.3 |
| 28 | 1 | 303.0 |
| 29 | 1 | 303.0 |
| 30 | 6 | 38722.8 |
| 31 | 76 | 375206.6 |
| 32 | 1 | 1616.0 |
| 33 | 1 | 1616.0 |
| 34 | 34 | 329518.1 |
| 35 | 32 | 262194.0 |
| 36 | 1 | 507.0 |
| 37 | 1 | 1014.1 |
| 38 | 1 | 1014.1 |
| 39 | 1 | 1500.0 |
| 40 | 104 | 621144.3 |
| 41 | 1 | 3809.2 |
| 42 | 1 | 3809.2 |
| 43 | 1 | 205.7 |
| 44 | 4 | 35201.1 |
| 45 | 1 | 5050.0 |
| 46 | 1 | 5050.0 |
| 47 | 42 | 342673.1 |
| 48 | 1 | 20281.1 |
| 49 | 3 | 3193.8 |
| 50 | 3 | 3193.8 |
| 51 | 3 | 4145.2 |
| 52 | 1 | 10000.0 |
| 53 | 38 | 2271217.4 |
| 54 | 38 | 2271217.4 |
| 55 | 1 | 10520.8 |
| 56 | 2 | 776.4 |
| 57 | 6 | 97945.7 |
| 58 | 6 | 97945.7 |
| 59 | 3 | 12160.6 |
| 60 | 1 | 981.5 |
| | 1 | 12675.7 |

| | | |
|----|----|-----------|
| 1 | | |
| 2 | 1 | 262.3 |
| 3 | 7 | 81316.2 |
| 4 | 5 | 47893.8 |
| 5 | 8 | 55592.3 |
| 6 | 7 | 1881.6 |
| 7 | 1 | 420.8 |
| 8 | 1 | 0.0 |
| 9 | 1 | 0.0 |
| 10 | 6 | 9784.6 |
| 11 | 12 | 95961.9 |
| 12 | 1 | 243.4 |
| 13 | 4 | 9320.3 |
| 14 | 26 | 249099.2 |
| 15 | 13 | 29164.3 |
| 16 | 57 | 1817634.9 |
| 17 | 1 | 0.0 |
| 18 | 7 | 6270.9 |
| 19 | 5 | 2338.0 |
| 20 | 1 | 4089.1 |
| 21 | 1 | 1000.0 |
| 22 | 2 | 624.9 |
| 23 | 2 | 16010.0 |
| 24 | 1 | 736.5 |
| 25 | 1 | 252.5 |
| 26 | 12 | 86711.0 |
| 27 | 2 | 120.9 |
| 28 | 3 | 5412.1 |
| 29 | 1 | 1028.5 |
| 30 | 3 | 20369.3 |
| 31 | 1 | 4187.3 |
| 32 | 9 | 27581.2 |
| 33 | 9 | 24748.9 |
| 34 | 17 | 281196.7 |
| 35 | 1 | 1892.5 |
| 36 | 1 | 526.0 |
| 37 | 3 | 14664.9 |
| 38 | 1 | 2592.9 |
| 39 | 3 | 6594.9 |
| 40 | 4 | 1547.3 |
| 41 | 1 | 15150.0 |
| 42 | 5 | 10786.9 |
| 43 | 2 | 1384.1 |
| 44 | 2 | 804.5 |
| 45 | 2 | 767.3 |
| 46 | 2 | 4085.1 |
| 47 | 7 | 6116.9 |
| 48 | 1 | 507.0 |

| | | |
|----|----|----------|
| 1 | | |
| 2 | 6 | 26164.4 |
| 3 | 2 | 11930.2 |
| 4 | 1 | 153.6 |
| 5 | 2 | 6400.0 |
| 6 | 2 | 6400.0 |
| 7 | 57 | 577521.6 |
| 8 | 10 | 13720.9 |
| 9 | 1 | 4000.0 |
| 10 | 1 | 4000.0 |
| 11 | 1 | 150.0 |
| 12 | 1 | 37.6 |
| 13 | 1 | 757.5 |
| 14 | 1 | 757.5 |
| 15 | 1 | 5070.3 |
| 16 | 13 | 63461.6 |
| 17 | 1 | 2104.2 |
| 18 | 1 | 2104.2 |
| 19 | 2 | 4156.5 |
| 20 | 1 | 4000.0 |
| 21 | 1 | 4000.0 |
| 22 | 11 | 29891.2 |
| 23 | 1 | 30322.2 |
| 24 | 1 | 2000.0 |
| 25 | 1 | 2000.0 |
| 26 | 10 | 91665.0 |
| 27 | 9 | 101336.2 |
| 28 | 37 | 183714.4 |
| 29 | 2 | 754.3 |
| 30 | 2 | 754.3 |
| 31 | 1 | 1010.0 |
| 32 | 1 | 353.5 |
| 33 | 1 | 353.5 |
| 34 | 4 | 22216.1 |
| 35 | 1 | 518.7 |
| 36 | 1 | 252.5 |
| 37 | 1 | 252.5 |
| 38 | 24 | 248299.0 |
| 39 | 1 | 0.0 |
| 40 | 4 | 55502.5 |
| 41 | 4 | 55502.5 |
| 42 | 1 | 707.0 |
| 43 | 1 | 15.2 |
| 44 | 3 | 3412.9 |
| 45 | 2 | 764.6 |
| 46 | 2 | 764.6 |
| 47 | 1 | 883.8 |
| 48 | 1 | 202.0 |
| 49 | 1 | 202.0 |
| 50 | 3 | 643.0 |
| 51 | 1 | 15000.0 |
| 52 | 24 | 386833.4 |
| 53 | 7 | 34571.2 |
| 54 | 7 | 34571.2 |
| 55 | 2 | 280.0 |
| 56 | 1 | 1010.0 |
| 57 | 1 | 1010.0 |
| 58 | 6 | 44237.3 |
| 59 | 1 | 6084.3 |
| 60 | 1 | 505.0 |
| | 1 | 603.4 |

| | | |
|----|----|----------|
| 1 | | |
| 2 | 1 | 2020.0 |
| 3 | 1 | 1420.3 |
| 4 | 1 | 0.0 |
| 5 | 1 | 152.1 |
| 6 | 1 | 1000.0 |
| 7 | 1 | 1000.0 |
| 8 | 14 | 23675.7 |
| 9 | 30 | 396718.0 |
| 10 | 30 | 396718.0 |
| 11 | 3 | 3508.5 |
| 12 | 35 | 326740.6 |
| 13 | 3 | 6650.0 |
| 14 | 3 | 6650.0 |
| 15 | 4 | 5775.3 |
| 16 | 1 | 1028.5 |
| 17 | 1 | 1028.5 |
| 18 | 2 | 4035.1 |
| 19 | 2 | 2080.6 |
| 20 | 2 | 2080.6 |
| 21 | 1 | 3400.0 |
| 22 | 1 | 510.9 |
| 23 | 2 | 3334.2 |
| 24 | 2 | 4184.1 |
| 25 | 2 | 4184.1 |
| 26 | 6 | 64181.1 |
| 27 | 3 | 24720.6 |
| 28 | 3 | 24720.6 |
| 29 | 10 | 4636.2 |
| 30 | 11 | 16888.4 |
| 31 | 10 | 30100.6 |
| 32 | 48 | 345520.4 |
| 33 | 48 | 345520.4 |
| 34 | 5 | 29848.9 |
| 35 | 1 | 400.0 |
| 36 | 1 | 8500.0 |
| 37 | 1 | 8500.0 |
| 38 | 4 | 2654.7 |
| 39 | 1 | 10000.0 |
| 40 | 4 | 68956.0 |
| 41 | 4 | 68956.0 |
| 42 | 1 | 151.5 |
| 43 | 1 | 0.0 |
| 44 | 1 | 473.4 |
| 45 | 1 | 473.4 |
| 46 | 3 | 563.8 |
| 47 | 1 | 1052.1 |
| 48 | 1 | 639.6 |
| 49 | 1 | 639.6 |
| 50 | 13 | 79339.8 |
| 51 | 1 | 579.3 |
| 52 | 1 | 1010.0 |
| 53 | 1 | 1010.0 |
| 54 | 62 | 682970.9 |
| 55 | 5 | 12939.6 |
| 56 | 1 | 736.5 |
| 57 | 1 | 252.5 |
| 58 | 1 | 771.4 |
| 59 | 1 | 771.4 |
| 60 | 70 | 770325.1 |
| | 1 | 354.9 |

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|----|----|----------|
| 1 | | |
| 2 | 2 | 720.7 |
| 3 | 1 | 4500.0 |
| 4 | 7 | 83686.8 |
| 5 | 1 | 277.7 |
| 6 | 1 | 1028.5 |
| 7 | 2 | 4056.2 |
| 8 | 2 | 78625.5 |
| 9 | 1 | 505.0 |
| 10 | 3 | 1139.3 |
| 11 | 1 | 473.4 |
| 12 | 2 | 514.3 |
| 13 | 1 | 151.5 |
| 14 | 1 | 210.4 |
| 15 | 1 | 224.0 |
| 16 | 12 | 117958.9 |
| 17 | 8 | 19924.8 |
| 18 | 3 | 7327.7 |
| 19 | 2 | 10120.3 |
| 20 | 1 | 1010.0 |
| 21 | 1 | 252.5 |
| 22 | 1 | 1052.1 |
| 23 | 4 | 62950.0 |
| 24 | 1 | 151.5 |
| 25 | 2 | 2334.0 |
| 26 | 1 | 1000.0 |
| 27 | 13 | 148469.6 |
| 28 | 1 | 5050.0 |
| 29 | 9 | 170502.5 |
| 30 | 2 | 5736.5 |
| 31 | 17 | 45782.5 |
| 32 | 2 | 1531.9 |
| 33 | 1 | 15150.0 |
| 34 | 1 | 151.5 |
| 35 | 3 | 4208.3 |
| 36 | 1 | 4056.2 |
| 37 | 3 | 38407.4 |
| 38 | 1 | 0.0 |
| 39 | 1 | 405.6 |
| 40 | 18 | 103557.2 |
| 41 | 1 | 257.6 |
| 42 | 1 | 5000.0 |
| 43 | 15 | 342275.9 |
| 44 | 1 | 0.0 |
| 45 | | |
| 46 | | |
| 47 | | |
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Web Supplement 16. Shared ties in industry and patient organisation data based on the number an**Ties calculated based on the number of payments**

Total number of ties reported in industry data involving at least one payment

Total number of ties reported in patient organisation data involving at least one payment

Number of shared ties (donors and recipients are the same in industry and patient organisation data)

Shared ties as a share of all ties in industry data

Shared ties as a share of all ties in patient organisation data

Number of ties involving the same number of payments

Number of ties involving the same number of payments as a share of shared ties

Number of payments forming ties with the equal number of payments in both datasets

Payments forming ties with the equal number of payments in both datasets as a share of all paymer

Payments forming ties with the equal number of payments in both datasets as a share of all paymer

Ties calculated based on the value of payments

Total number of ties reported in industry data involving at least one payment with value >£0

Total number of ties reported in patient data involving at least one payment with value >£0

Number of shared ties (donors and recipients are the same in industry and patient organisation data)

Shared ties as a share of all ties in industry data

Shared ties as a share of all ties in patient organisation data

Number of shared ties involving the same value of payments

Shared ties involving the same alue of payments as a share of shared ties

Value of payments in which donors and recipients provided the same value (2016 £)

Value of shared payments as a share of payments with values >£0 in industry data

Value of shared payments as a share of payments with values >£0 in patient organisation data

| | All years | 2012 | 2013 | 2014 | 2015 | 2016 |
|----|------------------|-------------|-------------|-------------|-------------|-------------|
| 1 | | | | | | |
| 2 | | | | | | |
| 3 | | | | | | |
| 4 | | | | | | |
| 5 | | | | | | |
| 6 | 1101 | 369 | 366 | 432 | 479 | 523 |
| 7 | 626 | 252 | 276 | 293 | 319 | 287 |
| 8 | | | | | | |
| 9 | | | | | | |
| 10 | 428 | 110 | 122 | 146 | 168 | 160 |
| 11 | 38.9% | 29.8% | 33.3% | 33.8% | 35.1% | 30.6% |
| 12 | 68.4% | 43.7% | 44.2% | 49.8% | 52.7% | 55.7% |
| 13 | | | | | | |
| 14 | | | | | | |
| 15 | 87 | 45 | 66 | 69 | 89 | 64 |
| 16 | 20.3% | 40.9% | 54.1% | 47.3% | 53.0% | 40.0% |
| 17 | | | | | | |
| 18 | | | | | | |
| 19 | 162 | 47 | 69 | 79 | 97 | 73 |
| 20 | 3.8% | 6.1% | 9.8% | 9.6% | 10.4% | 6.7% |
| 21 | 9.8% | 16.2% | 21.2% | 22.8% | 26.9% | 21.7% |
| 22 | | | | | | |
| 23 | | | | | | |
| 24 | | | | | | |
| 25 | | | | | | |
| 26 | | | | | | |
| 27 | 1088 | 366 | 357 | 431 | 470 | 522 |
| 28 | 326 | 127 | 122 | 119 | 150 | 140 |
| 29 | | | | | | |
| 30 | | | | | | |
| 31 | 34 | 21 | 24 | 28 | 32 | 24 |
| 32 | 3.1% | 5.7% | 6.7% | 6.5% | 6.8% | 4.6% |
| 33 | 10.4% | 16.5% | 19.7% | 23.5% | 21.3% | 17.1% |
| 34 | | | | | | |
| 35 | | | | | | |
| 36 | 20 | 17 | 22 | 26 | 30 | 23 |
| 37 | 58.8% | 81.0% | 91.7% | 92.9% | 93.8% | 95.8% |
| 38 | | | | | | |
| 39 | | | | | | |
| 40 | 325,108.4 | 216,055.8 | 201,362.3 | 251,964.6 | 517,139.2 | 482,216.0 |
| 41 | 0.6% | 2.8% | 3.3% | 2.9% | 4.5% | 2.4% |
| 42 | 1.0% | 6.2% | 4.6% | 4.8% | 10.7% | 3.2% |
| 43 | | | | | | |
| 44 | | | | | | |
| 45 | | | | | | |
| 46 | | | | | | |
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| 48 | | | | | | |
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| 54 | | | | | | |
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| 60 | | | | | | |

Web Supplement 17. Overlap between recipient lists reported by donors and patient organisations

| | Total number of donors with at least one payment | Minimum overlap with patient organisation data | Number of donors with minimum overlap with patient organisation data | Donors with minimum overlap with patient organisation data as a share of all donors | Number of donors with less than 50% overlap with patient organisation data | Donors with less than 50% overlap with patient organisation data as a share of all donors |
|-----------|--|--|--|---|--|---|
| All years | 63 | 0.0% | 6 | 9.5% | 40 | 63.5% |
| 2012 | 30 | 0.0% | 7 | 23.3% | 23 | 76.7% |
| 2013 | 38 | 0.0% | 9 | 23.7% | 25 | 65.8% |
| 2014 | 45 | 0.0% | 12 | 26.7% | 35 | 77.8% |
| 2015 | 51 | 0.0% | 11 | 21.6% | 33 | 64.7% |
| 2016 | 44 | 0.0% | 10 | 22.7% | 32 | 72.7% |

ation data - yearly breakdown based on the number of payments

| Maximum overlap with patient organisation data | Number of donors with maximum overlap with patient organisation data | Donors with maximum overlap with patient organisation data as a share of all donors |
|--|--|---|
| 100.0% | 3 | 4.8% |
| 100.0% | 1 | 3.3% |
| 100.0% | 4 | 10.5% |
| 100.0% | 3 | 6.7% |
| 100.0% | 3 | 5.9% |
| 100.0% | 3 | 6.8% |

For peer review only

Web Supplement 18. Overlap between recipient lists reported by donors and patient organisatio

| | Number of donors with at least one payemnt with the value >£0 | Minimum overlap with patient organisation data | Number of donors with minium overlap with patient organisation data | Donors with minium overlap with patient organisation data as a share of all donors | Number of donors with less than 50% overlap with patient organisation data | Donors with less than 50% overlap with patient organisation data as a share of all donors |
|-----------|---|--|---|--|--|---|
| All years | 62 | 0.0% | 17 | 27.4% | 56 | 90.3% |
| 2012 | 30 | 0.0% | 13 | 43.3% | 29 | 96.7% |
| 2013 | 38 | 0.0% | 18 | 47.4% | 36 | 94.7% |
| 2014 | 45 | 0.0% | 26 | 57.8% | 45 | 100.0% |
| 2015 | 50 | 0.0% | 21 | 42.0% | 42 | 84.0% |
| 2016 | 44 | 0.0% | 15 | 34.1% | 39 | 88.6% |

in data - yearly breakdown based on the value of payments

| Maximum overlap with patient organisation data | Number of donors with maximum overlap with patient organisation data | Donors with maximum overlap with patient organisation data as a share of all donors |
|--|--|---|
| 100.0% | 2 | 3.2% |
| 50.0% | 1 | 3.3% |
| 66.7% | 1 | 2.6% |
| 40.0% | 1 | 2.2% |
| 100.0% | 1 | 2.0% |
| 66.7% | 1 | 2.3% |

For peer review only

Web Supplement 19. Overlap between donor lists reported by recipients and industry data - y

| | Number of recipients with at least 1 payment | Minimum overlap with industry data | Number of recipients with minimum overlap with industry data | Recipients with minimum overlap with industry data as a share of all recipients | Number of recipients with less than 50% overlap with industry data | Recipients with less than 50% overlap with industry data as a share of all recipients |
|-----------|--|------------------------------------|--|---|--|---|
| All years | 200 | 0.0% | 14 | 7.0% | 32 | 16.0% |
| 2012 | 103 | 0.0% | 37 | 35.9% | 51 | 49.5% |
| 2013 | 102 | 0.0% | 38 | 37.3% | 50 | 49.0% |
| 2014 | 116 | 0.0% | 34 | 29.3% | 49 | 42.2% |
| 2015 | 126 | 0.0% | 37 | 29.4% | 47 | 37.3% |
| 2016 | 117 | 0.0% | 28 | 23.9% | 40 | 34.2% |

yearly breakdown based on the number of payments

| | Number of recipients with maximum overlap with industry data | Recipeints with maximum overlap with industry data as a share of all recipients |
|------------------------------------|--|---|
| Maximum overlap with industry data | 102 | 51.0% |
| 100.0% | 29 | 28.2% |
| 100.0% | 24 | 23.5% |
| 100.0% | 41 | 35.3% |
| 100.0% | 49 | 38.9% |
| 100.0% | 50 | 42.7% |

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Web Supplement 20. Overlap between donor lists reported by recipients and industry data - yearl

| | Number of patient organisations with at least one payment with the value >0 | Minimum overlap with industry data | Number of recipients with minimum overlap with industry data | Recipients with minimum overlap with industry data as a share of all recipients | Number of recipients with less than 50% overlap with industry data | Recipients with less than 50% overlap with industry data as a share of all recipients |
|-----------|---|------------------------------------|--|---|--|---|
| All years | 121 | 0.0% | 12 | 9.9% | 18 | 14.9% |
| 2012 | 57 | 0.0% | 22 | 38.6% | 30 | 52.6% |
| 2013 | 51 | 0.0% | 19 | 37.3% | 26 | 51.0% |
| 2014 | 58 | 0.0% | 17 | 29.3% | 21 | 36.2% |
| 2015 | 72 | 0.0% | 22 | 30.6% | 26 | 36.1% |
| 2016 | 57 | 0.0% | 10 | 17.5% | 15 | 26.3% |

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2 **ly breakdown based on the value of payments**
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| | Number of recipients with maximum overlap with industry data | Receipts with maximum overlap with industry data as a share of all recipients |
|------------------------------------|--|---|
| Maximum overlap with industry data | 71 | 58.7% |
| | 16 | 28.1% |
| | 14 | 27.5% |
| | 27 | 46.6% |
| | 35 | 48.6% |
| | 31 | 54.4% |

STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

| | Item No | Recommendation | Page No |
|---------------------------|---------|---|------------------------|
| Title and abstract | 1 | (a) Indicate the study's design with a commonly used term in the title or the abstract | 4 |
| | | (b) Provide in the abstract an informative and balanced summary of what was done and what was found | 4 |
| Introduction | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 5 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | 5 |
| Methods | | | |
| Study design | 4 | Present key elements of study design early in the paper | 6 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 6 |
| Participants | 6 | (a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up | 6 |
| | | (b) For matched studies, give matching criteria and number of exposed and unexposed | N/A |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 7 |
| Data sources/measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | 7 |
| Bias | 9 | Describe any efforts to address potential sources of bias | 6 |
| Study size | 10 | Explain how the study size was arrived at | 6 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | 7 |
| Statistical methods | 12 | (a) Describe all statistical methods, including those used to control for confounding | 7 |
| | | (b) Describe any methods used to examine subgroups and interactions | N/A |
| | | (c) Explain how missing data were addressed | 6 |
| | | (d) If applicable, explain how loss to follow-up was addressed | N/A |
| | | (e) Describe any sensitivity analyses | N/A |
| Results | | | |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 7 |
| | | (b) Give reasons for non-participation at each stage | N/A |
| | | (c) Consider use of a flow diagram | Web supplement 1 and 2 |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | 7-8 |
| | | (b) Indicate number of participants with missing data for each variable of interest | 6,16 |
| | | (c) Summarise follow-up time (eg, average and total amount) | Table 1 |
| Outcome data | 15* | Report numbers of outcome events or summary measures over time | 7-20 |

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|----|--------------------------|----|--|-------|
| 1 | Main results | 16 | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 7-20 |
| 2 | | | (b) Report category boundaries when continuous variables were categorized | 10-15 |
| 3 | | | (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | N/A |
| 4 | Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | N/A |
| 5 | Discussion | | | |
| 6 | Key results | 18 | Summarise key results with reference to study objectives | 20-22 |
| 7 | Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 22-23 |
| 8 | Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 23 |
| 9 | Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 22 |
| 10 | Other information | | | |
| 11 | Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 2 |

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.

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An underreported relationship: a comparative study of pharmaceutical industry and patient organisation payment disclosures in the UK (2012-2016)

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An underreported relationship: a comparative study of pharmaceutical industry and patient organisation payment disclosures in the UK (2012-2016)

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Key words: pharmaceutical industry, patient organisations, conflicts of interest, financial disclosures, transparency

Wordcount: 4,455

Abstract

Objectives: To examine the underreporting of pharmaceutical company payments to patient organisations by donors and recipients.

Design: Comparative descriptive analysis of payments disclosed on drug company and charity regulator websites.

Setting: UK.

Participants: 87 donors (drug companies) and 425 recipients (patient organisations) reporting payments in 2012-2016.

Main outcome measures: Number and value of payments reported by donors and recipients; differences in reported payments from/to the same donors and recipients; payments reported in either dataset but not the other one; agreement between donor-recipient ties established by payments; overlap between donor and recipient lists and, respectively, industry and patient organisation data.

Results: Of 87 donors, 63 (72.4%) reported payments but 84 (96.6%) were mentioned by recipients. Although donors listed 425 recipients, only 200 (47.1%) reported payments. The number and value of payments reported by donors were 259.8% and 163.7% greater than those reported by recipients, respectively. The number of donors with matching payment numbers and values in both datasets were 3.4% and 0%, respectively; for recipients these figures were 7.8% and 1.9%. There were 24 and 3 donors missing from industry and patient organisation data during the entire study period, representing 38.1% and 3.6% of those in the respective datasets. The share of donor-recipient ties in which industry and patient organisation data agreed about donors and recipients was 38.9% and 68.4% in each dataset, respectively. Of 63 donors reporting payments, only 3 (4.8%) had their recipient lists fully overlapping with patient organisation data. Of 200 recipients reporting industry funding, 102 (51.0%) had their donor lists fully overlapping with industry data.

Conclusions: Both donors and recipients underreported payments. Existing donor and recipient disclosure systems cannot manage potential conflicts of interest associated with industry payments. Increased standardisation could limit the underreporting by each side but only an integrated donor-recipient database could eliminate it.

Strengths and limitations

- We examine the underreporting of pharmaceutical industry payments to patient organisations using large samples of donors and recipients over a period of time
- We systematically compare the underreporting by donors and recipients using five complementary measures at different levels of analysis
- One key limitation is that the samples of donors and recipients were not exhaustive
- The full extent of underreporting remains unknown as no definitive list of payments exists

Introduction

Many patient organisations accept funding from drug companies. A recent UK analysis showed that the industry donated over £57m (€65m; \$73m) to 508 patient organisations, with the annual sum more than doubling from 2012 to 2016.¹ Another study of 289 US patient organisations found that 156 (67%) received funding from for-profit companies, with a median proportion of 45% of their income coming from drug, medical device, or biotechnology companies.² Although industry funding may benefit patient organisations,^{3 4} it raises concerns about potential conflict of interests (COIs) compromising patient organisations' independence and credibility.^{5 6 7 8 9 10}

Both donors¹¹ and recipients⁴ assert that any COIs can be managed by careful disclosure of funding. On the donor side, since 2012 members of pharmaceutical industry trade groups in European countries,¹² such as the Association of the British Pharmaceutical Industry (ABPI), have disclosed payments to patient organisations annually on each company's website, including their monetary value and purpose.¹³ In the UK, the number of companies subscribing to the ABPI Code also includes over sixty non-members of the ABPI; hence, nearly every relevant company is covered.¹⁴ However, the self-regulatory approach to payment disclosure has shortcomings, including absent reports, unclear or inadequate payment descriptions, and unstandardised reporting.^{1 15} Likewise, on the recipient side, disclosures published on patient organisations' websites have been criticised as incomplete or uninformative.^{16 17 18 19 20} In the UK, a possibly more reliable, yet rarely examined,^{15 21} source of disclosures are mandatory annual accounts of patient organisations registered as charities with an annual income over £25,000. These accounts serve a dual-purpose of detailing the charity's activities and ensuring financial transparency.

Notwithstanding the shortcomings of each side's disclosures, and the potentially complementary information they provide, donor and recipient disclosures are rarely compared. One exception is a recent UK study which identified companies not disclosing payments to patient organisations being mentioned in their annual accounts as donors.¹⁵ Another UK study found discrepancies between annual accounts of some patient organisations contributing to health technology assessment in England and drug company payment disclosures.²¹ Similarly, discrepancies were found between sponsorships reported on patient organisation and drug company websites in Italy.¹⁹ More broadly, cross-interrogation of different data sources has revealed undisclosed industry ties among treatment guideline panellists,^{22 23 24} clinical trialists, authors of medical journal articles,^{25 26 27 28 29} and some clinical commissioning groups³⁰ and NHS trusts in England.³¹

We examine the underreporting of payments to UK patient organisations from 2012 to 2016 by comparing payment disclosures made by 87 companies to 425 patient organisations with the annual accounts of the same set of patient organisations. Specifically, by considering the extent to which the industry and patient organisation disclosures differ regarding who provided and received funding, and how much was paid and received, we examine the reliability of the two disclosures systems said to neutralise concerns about COIs.

Methods

Data sources and extraction

Absent of a complete list of non-ABPI member companies that subscribe to the ABPI Code, our sample of drug companies comprised all 108 participants of Disclosure UK in 2015, including 53 ABPI members and 55 non-members (web supplement 1). Disclosure UK is a self-regulatory initiative run by the ABPI, covering payments to healthcare organisations³² and professionals,³³ but because its participants subscribe to the ABPI Code, they should also separately disclose, on their websites, payments to patient organisations once a year.^{1 15}

In June 2017 and January 2018, ER searched the websites of the 108 companies, identifying 220 disclosure reports published between 2012 and 2016. ER downloaded them and extracted payment data into a single Excel spreadsheet, converting all payment values to 2016 sterling using inflation data from the Office for National Statistics.³⁴ There were 66 (61.1%) companies disclosing payments in at least one year during this period. Following the exclusion of ineligible payments based on their timing or recipient characteristics, we established that 64 companies reported 4,572 payments, worth £57,305,289.2 to 489 UK patient organisations (web supplement 1).

In September 2017 and July 2018, ER searched for these patient organisations on the websites of the UK charity regulators – the Charity Commission for England and Wales, the Scottish Charity Regulator and the Northern Irish Charity Regulator – to which registered charities must submit their annual accounts. We considered accounts from financial years ending in 2012 to 2017 to cover all calendar year data from drug company reports. We found that 425 (86.9%) patient organisations drug companies listed as recipients published their annual accounts at least once with at least one charity regulator, with the total number of annual accounts of 1,428. In industry data, 63 (98.4%) companies reported 4,316 (94.4%) payments, worth £54,071,454.21 (94.4%) to these patient organisations.

ER read all annual accounts and extracted any information pertaining to drug company payments to an Excel spreadsheet. As with industry data, if several values were mentioned in a single payment description they were considered as separate payments. As patient organisation yearly accounts lack specific monthly end date,²¹ we turned those covering months up to June into the previous calendar year, and the rest into the current calendar year. The 425 patient organisations registered as charities reported 4,372 payments, worth £58,668,293.6, from 167 donors. Following exclusion criteria referring to donor and recipient characteristics as well as the conversion of financial into calendar years (web supplement 2), we established that 200 (47.1%) organisations reported 1,661 (38.0%) payments, worth £33,037,955.8 (56.3%), from 84 (47.1%) drug companies. Notably, we excluded 2,014 payments, worth £1,992,147.3, made by 61 companies found in patient organisation data but missing from the original sample of Disclosure UK participants.

One researcher, ER, collected drug company disclosure reports and patient organisation annual accounts. Drug company and charity regulator websites are well-structured and ER searched the websites at two points in time, with the second phase of data collection being used to check the accuracy of the initial one. Therefore, we are confident that no relevant

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3 documents were missed. When extracting payment data from drug company and patient
4 organisation documents into Excel spreadsheets, ER checked twice that each payment was
5 transferred correctly. As these documents follow a similar format we deemed it sufficient for
6 another researcher, PO, to check 20% randomly selected drug company payment disclosure
7 reports and patient organisation annual accounts with no discrepancies found.
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10 The ethical implications of this study article were approved via a peer ethics review
11 process at the Department of Social and Policy Sciences, University of Bath in April 2016.
12 This study did not require a full ethical approval as it relied on publicly available data
13 aggregated at the organisational level.
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16 Analysis

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18 MC and PO converted the data into donor-recipient matrices and analysed it descriptively in
19 Excel. We examined the overall pattern of the number and value of payments in each
20 dataset and its changes over time.
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23 Outcome measures

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25 Absent an exhaustive list of payments, enabling a direct comparison of industry and patient
26 organisation data, we studied underreporting with five complementary measures. Our
27 calculations can be verified by consulting web supplements 3-20 signposted throughout the
28 Results. The web supplements are accessible via the University of Bath Research Data
29 Archive in the Excel format.³⁵
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33 First, we compared the overall volume of payments reported in industry and patient
34 organisation data, including payments lacking specific values.
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37 Second, we examined the absolute and relative differences in payments reported in relation
38 to the same donors and recipients in industry and patient organisation data. We calculated
39 the absolute difference as the difference between the number/value of payments reported in
40 the two datasets; the relative difference was the absolute difference divided by the
41 number/value of payments in the dataset with the higher number/value of payments. To
42 compare larger and smaller donors and recipients we considered absolute and relative
43 differences at different thresholds of the overall number (i.e. ≥ 1 , > 1 , > 10 , > 100 in at least one
44 dataset) and value of payments (i.e. $> \text{£}0$, $> \text{£}10,000$, $> \text{£}100,000$ in at least one dataset).
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47 Third, focusing on the highest relative differences, in which donors or recipients were present
48 in one but absent from the other dataset, we calculated the number and value of payments
49 related to donors and recipients missing from each dataset.
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52 Fourth, we compared the extent to which industry and patient organisation data conveyed
53 the same pattern of connections between donors and recipients. Specifically, we analysed
54 the overlap of ties (or connections) between donors and recipients – established by the
55 presence of payments – in each dataset.
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3 Finally, building on the analysis of donor-industry ties at the level of the two datasets, we
4 moved to the donor and recipient level by examining the extent of overlap between recipient
5 and donor lists in patient organisation and industry data, respectively.
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7 **Patient and public involvement**

8 Neither patient groups nor the public were involved in this study. We plan to disseminate
9 key findings in an accessible format using a blog post.
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12 **Results**

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16 The Results follow the measures of underreporting of payments outlined in the Methods. We
17 summarise relationships between these measures in Figure 1.
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19 [Figure 1]
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23 **Comparison of payment patterns in industry and patient organisation data**

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26 Although 63 donors reported payments, 84 were mentioned by recipients. In industry data,
27 donors disclosed payments to 425 recipients but only 200 (47.1%) of those reported
28 payments during the study period (Table 1).
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30
31 The number of payments disclosed by donors was 259.8% greater than those disclosed by
32 recipients (Table 1). Each side was disclosing more payments over time, but the increase
33 from 2012 to 2016 was greater in industry data (141.2% v 115.8%, respectively). In industry
34 data, 4,235 (98.1%) payments reported by 62 (98.4%) donors to 416 (97.9%) recipients had
35 values greater than 0. In patient organisation data, only 772 (46.5%) payments reported by
36 121 (60.5%) recipients from 62 (73.8%) donors had values greater than 0. The value of
37 payments disclosed by donors was 163.7% higher than those disclosed by recipients. Over
38 the five-year period the value of payments reported by donors increased by 257.6%, while
39 those by recipients – by 434.7%.
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Table 1 Patterns in payments reported by donors and recipients*

| | All years | 2012 | 2013 | 2014 | 2015 | 2016 |
|--|--------------|-------------|-------------|-------------|--------------|--------------|
| Calculations based on the number of payments | | | | | | |
| Number of payments - industry data | 4316 | 769 | 706 | 821 | 934 | 1086 |
| Number of payments - patient organisation data | 1661 | 291 | 326 | 346 | 361 | 337 |
| Number of drug companies with at least one payment - industry data | 63 | 30 | 38 | 45 | 51 | 44 |
| Number of drug companies with at least one payment - patient organisation data | 84 | 56 | 65 | 65 | 69 | 65 |
| Number of patient organisations with at least one payment - industry data | 425 | 197 | 198 | 225 | 244 | 244 |
| Number of patient organisations with at least one payment - patient organisation data | 200 | 103 | 102 | 116 | 126 | 117 |
| Calculations based on the value of payments | | | | | | |
| Number of payments with value >£0 - industry data | 4235 | 748 | 682 | 813 | 915 | 1077 |
| Number of payments with value >£0 - patient organisation data | 772 | 144 | 148 | 144 | 173 | 163 |
| Value of payments - industry data (2016 £) | 54,071,454.2 | 7,797,600.4 | 6,189,152.7 | 5,583,101.6 | 11,415,293.2 | 20,086,306.3 |
| Value of payments - patient organisation data (2016 £) | 33,037,955.8 | 3,459,605.6 | 4,414,328.4 | 3,301,728.3 | 4,825,091.2 | 15,037,202.3 |
| Number of drug companies with at least one payment with the value >£0 - industry data | 62 | 30 | 38 | 45 | 50 | 44 |
| Number of drug companies with at least one payment with the value >£0 - patient organisation data | 62 | 42 | 44 | 42 | 46 | 44 |
| Number of patient organisations with at least one payment with the value >£0 - industry data | 416 | 197 | 193 | 225 | 237 | 244 |
| Number of patient organisations with at least one payment with the value >£0 - patient organisation data | 121 | 57 | 51 | 58 | 72 | 57 |

* We used the following values of the Consumer Price Index obtained from Office for National Statistics to adjust payment values for inflation: 2012=96, 2013=98.2, 2014=99.6, 2015=100, 2016=101.

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Payments reported in relation to the same donors and recipients in industry and patient organisation data

Having considered the overall pattern of payments, we now compare those reported in relation to the same donors and recipients in each dataset.

Donors

Of the 87 donors identified in industry and patient organisation data, three (3.4%) had matching payment numbers, and 49 (56.3%) had more payments in patient organisation data (Table 2; web supplement 3). In relative terms, only 21 (24.1%) donors had a difference in the number of payments less than 50%, and 27 (31.0%) had a difference of 100%, equivalent to only either donors or recipients reporting payments.

In both datasets, 74 (85.1%) donors had payment values greater than 0 (web supplement 3). Of those, 48 (64.9%) had a higher payment value in industry data and the remaining ones – in patient organisation data. Only 14 (18.9%) donors with payment values greater than 0 had a relative difference lower than 50%, while 24 (32.4%) donors had a relative difference of 100%.

Overall, donors with a high overall number and value of payments in either dataset typically had high absolute differences (web supplement 3). Contrastingly, donors with a small number or value of payments usually had higher relative differences, that is, high relative differences often resulted from few payments or payments of small value in one dataset but none in the other.

Over time, there was little improvement in the shares of donors with matching numbers of payments (from 1.6% in 2012 to 5.5% in 2016); the share of donors with matching payment values showed no improvement (0%). However, the shares of those with relative differences in payment numbers or values lower than 50% increased (from 11.5 to 17.4%; and from 7.7% to 25.5%, respectively) (web supplement 4).

Table 2 Donors – absolute and relative differences in the number and value of payments

| | All years | % |
|---|-----------|-------|
| Calculations based on the number of payments - absolute differences | | |
| Number of drug companies with at least one payment in at least one dataset - industry and patient organisation data | 87 | |
| Number of drug companies with exact match in both datasets | 3 | 3.4% |
| Number of drug companies with more payments in industry data | 49 | 56.3% |
| Number of drug companies with more payments in patient organisation data | 35 | 40.2% |
| Highest absolute difference between patient organisation and industry data - number of payments higher in industry data | 757 | |
| Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data | 53 | |
| Calculations based on the number of payments - relative differences | | |
| Number of drug companies with relative difference <10% | 5 | 5.7% |
| Number of drug companies with relative difference <20% | 9 | 10.3% |
| Number of drug companies with relative difference <50% | 21 | 24.1% |
| Number of drug companies with relative difference = 100% | 27 | 31.0% |
| Calculations based on the value of payments - absolute differences | | |
| Number of drug companies with at least one payment with value >£0 in at least one dataset | 74 | 100% |
| Number of drug companies with exact match in both datasets | 0 | 0.0% |
| Number of drug companies with higher payment value in industry data | 48 | 64.9% |
| Number of drug companies with higher payment value in patient organisation data | 26 | 35.1% |

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| 4 | Highest absolute difference between patient organisation and industry data - number of payments higher in industry data (2016 £) | 6,406,351.2 | |
| 5 | Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data (2016 £) | 2,960,716.0 | |
| 6 | | | |

Calculations based on the value of payments - relative differences

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|----|--|----|-------|
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| 10 | Number of drug companies with relative difference <10% | 3 | 4.1% |
| 11 | Number of drug companies with relative difference <20% | 9 | 12.2% |
| 12 | Number of drug companies with relative difference <50% | 14 | 18.9% |
| 13 | Number of drug companies with relative difference <50% | | |
| 14 | Number of drug companies with relative difference = 100% | 24 | 32.4% |
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Recipients

Of the 425 recipients identified in industry data, 33 (7.8%) had matching payments numbers in both datasets, while 335 (78.8%) had a greater number in industry data (Table 3, web supplement 5). In relative terms, 225 (52.9%) recipients had payments reported only in industry data (the relative difference of 100%), while 81 (19.1%) had a relative difference lower than 50%.

Of 425 recipients, 416 (97.9%) had payments with a value greater than 0 in at least one dataset (web supplement 5). Of those, 356 (85.6%) had a higher value of payments in industry data, and 8 (1.9%) had matching payment values. In relative terms, 295 (70.9%) recipients had payments reported exclusively in industry data, and 73 (17.5%) recipients had a relative difference lower than 50%.

Overall, recipients with a high overall number and value of payments usually had high absolute differences (web supplement 5). Relative differences were lower for recipients with higher overall number and value of payments.

The shares of recipients with matching numbers and values of payments showed no improvement over time, but the shares of those with relative differences lower than 50% increased (from 13.7% to 17.3% and from 9.7% to 14.5%, respectively) (web supplement 6).

Table 3 – Recipients – absolute and relative differences in the number and value of payments

| | All years | % |
|---|-----------|-------|
| Calculations based on the number of payments - absolute differences | | |
| Number of patient organisations with at least one payment in at least one dataset - industry and patient organisation data | 425 | |
| Number of patient organisations with exact match in both datasets | 33 | 7.8% |
| Number of patient organisations with more payments in industry data | 335 | 78.8% |
| Number of patient organisations with more payments in patient organisation data | 57 | 13.4% |
| Highest absolute difference between patient organisation and industry data - number of payments higher in industry data | 199 | |
| Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data | 33 | |
| Calculations based on the number of payments - relative differences | | |
| Number of patient organisations with relative difference <10% | 35 | 8.2% |
| Number of patient organisations with relative difference <20% | 42 | 9.9% |
| Number of patient organisations with relative difference <50% | 81 | 19.1% |
| Number of patient organisations with relative difference = 100% | 225 | 52.9% |
| Calculations based on the value of payments - absolute differences | | |
| Number of patient organisations with at least one payment with value >£0 in at least one dataset | 416 | 100% |
| Number of patient organisations with exact match in both datasets | 8 | 1.9% |
| Number of patient organisations with higher payment value in industry data | 356 | 85.6% |
| Number of patient organisations with higher payment value in patient organisation data | 52 | 12.5% |

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| 5 | Highest absolute difference between patient organisation and industry data - number of payments higher in industry data (2016 £) | 6,718,576.6 | |
| 6 | Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data (2016 £) | 6,493,237.1 | |
| 7 | | | |

Calculations based on the value of payments - relative differences

| | | | |
|----|---|-----|-------|
| 10 | | | |
| 11 | | | |
| 12 | Number of patient organisations with relative difference <10% | 21 | 5.0% |
| 13 | Number of patient organisations with relative difference <20% | 34 | 8.2% |
| 14 | Number of patient organisations with relative difference <50% | 73 | 17.5% |
| 15 | Number of patient organisations with relative difference = 100% | 295 | 70.9% |
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Missing payments

After analysing the pattern of absolute and relative differences we now focus on donors and recipients with the relative difference of 100%, that is, those with payments reported only in either industry or patient organisation data.

Industry data

There were 24 donors, representing 38.1% of those in industry data, which seemed not to comply with the ABPI Code¹³ as their payments were reported exclusively in patient organisation data over the entire period of observation (web supplement 7, 8, 9). The number and value of payments associated with these donors (in patient organisation data) were 128 and £1,610,321.1, equivalent to 3% of the number and value of payments in industry data. The annual shares of missing donors and their payments were considerably higher as some companies did not report payments only in some years. The annual shares of missing payments were decreasing over time.

Patient organisation data

There were 3 donors, constituting 3.6% of those in patient organisation data, whose payments were only reported in industry data (web supplement 10, 11, 12). The number and value of payments associated with these donors (in industry data) were 9 and £92,208.2, constituting 0.5% and 0.3% of the number and value of payments in patient organisation data. As with industry data, the annual shares of missing donors and their payments were higher as some donors were not reported in patient organisation data only in some years. The annual shares of missing payments were decreasing during the study period.

There were 225 recipients missing from patient organisation data, representing 112.5% of recipients in this dataset (web supplement 13, 14, 15). The number and value of missing payments were 1,472 and £14,023,475.41 (88.6% and 42.4% of the respective figures in patient organisation data). The yearly share of missing recipients and their payments increased, while the yearly share of missing payment values decreased.

Agreement between donor-recipient ties reported by industry and patient organisations

After describing the underreporting as a donor/recipient characteristic we now consider it by examining the distribution of ties between donors and recipients in each dataset

There were 1101 ties between donors and recipients formed by at least one payment in industry data and 626 in patient organisation data (Web Supplement 16). In 428 instances both datasets agreed about the donors and recipients, representing 38.9% and 68.4% of ties in each dataset, respectively. Of these, in 87 (20.3%) instances both donors and recipients reported the same number of payments. The number of payments constituting those matching ties was 162, equivalent to 3.8% and 9.8% of the total in industry and patient organisation data, respectively.

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3 There were 1,088 ties involving payments with a value greater than zero in industry data and
4 326 in patient organisation data. In 34 instances, both datasets agreed about donors and
5 recipients (3.1% and 10.4% of ties in each dataset). Of these, in 20 instances (58.8%)
6 instances both sides provided matching payment values. The ties with matching values were
7 worth £325,108.4, representing 0.6% and 1.0% of the value of payments in industry and
8 patient organisation data, respectively.
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11 The proportion of shared ties remained stable across time (web supplement 16).
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13 **Overlap between recipient and donor lists in the two datasets**

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16 Having compared the distribution of ties in each dataset, we now consider ties as a
17 characteristic of donors and recipients. Specifically, we analyse underreporting by comparing
18 donor and recipient lists in each dataset against the other dataset.
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20
21 Figure 2 Overlap between recipient and donor lists
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23 **Overlap between recipient lists and patient organisation data**

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26 Of 63 donors reporting at least one payment in the industry dataset, only 3 (4.8%) had all
27 their recipients mentioning them as donors, the situation representing the full overlap
28 between recipient lists and patient organisation data (Figure 2A). Conversely, the recipient
29 lists of 6 (9.5%) donors had zero overlap with patient organisation data. The recipient lists of
30 the remaining donors were situated between the two extremes, with 40 (63.5%) donors
31 having less than 50% overlap, meaning that only half of the recipients were reflected in
32 patient organisation data.
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34
35 Considering the recipient lists calculated using the value of payments (62 donors reporting
36 payment values greater than zero), the full and zero overlap occurred for 2 (3.2%) and 17
37 (27.0%) donors, respectively (Figure 2B). Overall, 56 (90.3%) donors had less than 50%
38 overlap with patient organisation data.
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40 **Overlap between donors lists and industry data**

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43 Of the 200 recipients in patient organisation data, 102 (51.0%) had all donors mentioning
44 them as recipients, which represented the full overlap between donor lists and industry data
45 (Figure 2C). Contrastingly, the donor lists of 14 (7.4%) recipients had no overlap with
46 industry data. Overall, 32 (16.0%) recipients had less than 50% overlap with industry data.
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50 Based on the value of payments (121 recipients reporting payment values greater than
51 zero), the full and zero overlap occurred for 71 (58.7%) and 12 (9.9%) recipients, respectively
52 (Figure 2D). There were 18 (14.9%) donors with less than 50% overlap with industry data.
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55 Over time, there was little improvement in the share of patient organisations reporting
56 funding from drug companies listing them as recipients (web supplement 17 and 18). On the
57 other hand, donors were reporting an increasing share of patient organisations mentioning
58 their funding (web supplement 19 and 20).
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Discussion

Principal findings

Our study confirms that earlier concerns about the underreporting of payments in relation to specific drug companies¹⁵ and charities^{36 37} in the UK were not isolated instances. It demonstrates that neither the industry self-regulatory system for disclosure of payments to patient organisations¹ nor a state-run system built for broader financial transparency purposes prevented a high extent of underreporting. Importantly, the underreporting occurred despite the media and research salience of the transparency of financial relationships between the industry and patient organisations.^{19 38 39 40}

Although some yearly variation might be expected given differences between when a payment was made and when it was received or spent, the overall large and seemingly increasing discrepancies between industry and patient organisation records are concerning. The number and value of payments disclosed by drug companies were likely to be higher because the ABPI Code has a formal definition of a payment and stipulates that payment values should be recorded whenever possible.¹³ Charity regulators lack similar specific requirements.⁴¹ Further, some patient organisations may redistribute money to other collaborators and therefore they may report smaller amounts than donating drug companies.⁴² Nevertheless, any differences between donor and recipient records should be minimised by the requirement for a written contract between the parties, introduced by the ABPI Code, implying a shared understanding of how much is paid, to whom, and how.¹³

What also indicates underreporting is that few companies and patient organisations had matching – or even broadly similar – records in the two datasets, with many having differences exceeding hundreds of payments or millions of pounds. Both drug companies and patient organisations had a larger number of payments in the other dataset, but for both sides the value of payments was greater in industry data. The contrast between the datasets was higher for patient organisations, with a majority having a greater number and value of payments reported in industry data. This pattern suggests inadequacies of the existing charity regulator governance of the reporting of corporate payments. It further corresponds with the results of a recent journalistic investigation into the underreporting of payments by a major charity,^{36 37} prompting a rebuke from a charity regulator.⁴³

We also unearthed unreported payments associated with companies missing from either dataset. The underreporting of payments is further indicated by the fact that donor-recipient ties reported in both datasets were in minority. This was particularly the case for ties involving matching payment numbers or values. The extent of the overlap between donor and recipient lists reported in the two datasets was similarly limited. Therefore, donors and recipients rarely disclosed payments reported by the other side.

As drug companies from our sample signed the ABPI Code, missing payments indicate that they either did not meet the obligation to disclose or removed their online disclosure reports. We could not find any evidence of specific obligations for UK charities to name funders in their accounts.⁴¹ Their absence is motivated by concerns that “the loss of donor anonymity would result in a decrease in voluntary income reported by charities. There were

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3 also concerns about the practical implications and about how much interest ‘general users’
4 of charity accounts would have in this disclosure.”⁴⁴ Nevertheless, any unreported payments
5 could be misleading for patient organisation members, supporters, expert bodies relying on
6 patient testimonies,²¹ policymakers, and the public.^{36 43} Unreported payments may indicate
7 a culture of corporate manipulation of patient organisations.^{45 46} Indeed, an oft-used
8 argument for increasing transparency of payments is that “sunshine” mitigates against
9 misbehaviour and undue influence.⁴⁷ Crucially, despite challenges in achieving financial
10 sustainability,⁴⁸ some patient organisations do not accept industry funding.^{49 50}
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14 Finally, underreporting should be minimised by codes and reporting standards seeking to
15 ensure faithful disclosure. The ABPI’s self-regulatory authority, the PMCPA, is tasked with
16 ensuring compliance under the ABPI Code, including through guidance and training,
17 occasional active monitoring, and with the possibility to sanction companies that breach
18 their obligations.^{51 52} Likewise, the UK Charity regulators monitor a selection of annual
19 accounts annually and, in instances of inaccurate reporting, will contact the charity directly
20 to provide advice or request the accounts be resubmitted.^{53 54 55}
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24 More broadly, a similarly high extent of underreporting was found in Italy, with less than a
25 third of patient organisations identified as funding recipients disclosing industry funding.¹⁹
26 High levels of underreporting have also been identified internationally in relation to other
27 recipients of industry payments, including authors of clinical practice guidelines^{23 24} and
28 scientific publications.^{26 27 29}
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31 **Strengths and limitations**

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33 This is the first study examining the underreporting of payments to patient organisations
34 using large samples of donors and recipients over a period of time. It systematically
35 compares the underreporting by the two sides using five complementary measures. These
36 measures account for the varying nature of different types of payment data and therefore
37 can be replicated elsewhere.
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41 Our study has several limitations. First, while Disclosure UK covers a vast majority of the UK
42 pharmaceutical industry,¹⁴ our sample was not exhaustive, as demonstrated by additional
43 companies found in patient organisation accounts. Second, excluding companies outside of
44 our sample is likely to have underestimated the underreporting but reach data saturation
45 would require several further rounds of data scrapping . Third, we identified patient
46 organisations using drug company disclosure reports, but sampling starting from patient
47 organisations could have produced different results. Fourth, patient organisations registered
48 with charity regulators but with yearly income lower than £25,000 are not required to
49 submit annual accounts. Therefore, we might have excluded, entirely or in specific years,
50 some of the patient organisations identified as recipients of industry funding, if their yearly
51 incomes were below that threshold. Fifth, some patient organisations were excluded due to
52 the conversion of financial years into calendar years, which might have increased
53 discrepancies with drug company disclosure reports. Sixth, some companies might have
54 reported payments from 2016 in subsequent years, but the extent of delayed reporting is
55 likely to have been minimal,¹ and there was no delayed reporting in patient organisation
56 annual accounts. Seventh, we only considered annual accounts submitted to charity
57 regulators, while funders might have also (or instead) been disclosed on the charity’s
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3 website. However, website disclosures are likely to undergo frequent changes, and often
4 lack transparency.^{16 17 18 19 20} Eight, evaluating the extent of underreporting precisely is
5 impossible because no definitive list of payments exists; consequently, there could be
6 payments undisclosed by both sides. Finally, considering payment descriptions could reveal
7 further discrepancies, including different payment goals reported by donors and recipients;
8 it could also identify payments made via third parties (e.g. public relations companies⁴³) or
9 benefitting patient organisations indirectly.¹⁵
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12 Conclusions and policy implications

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15 Although the full scale of underreporting of industry payments to patient organisations
16 remains unknown, it concerns both donors and recipients, and involves a considerable
17 number and value of payments. Our findings put a question mark over the key claim that –
18 at least in their current form – publicly available payment disclosures effectively address
19 concerns about COIs resulting from industry payments.
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22 We provide evidence for developing easily achievable improvements in the reporting of
23 payments by both donors and recipients. Consistent with the ABPI Code, the ABPI's self-
24 regulatory authority, the PMCPA, should investigate any instances of missing payments
25 among the companies that have ratified the Code (data never published or prematurely
26 removed from the public domain), and, if appropriate, penalise companies concerned in
27 accordance with its mandate and available financial (so-called administrative charges) and
28 non-financial (mainly naming and shaming) sanctions.^{51 52} Separately, drug companies
29 should improve data presentation following earlier recommendations,¹⁵ especially
30 standardisation of reporting and elimination of payments with no assigned values.
31 Companies should store data for at least as long as is required by the Charity Commission for
32 England and Wales, that is five years. Reduction in underreporting could also be achieved if
33 the ABPI started to publish yearly reports summarising payments to patient organisations
34 disclosed by companies, as the ABPI currently does with payments to healthcare
35 professionals and organisations in the Disclosure UK database.^{33 32} Indeed, at least one
36 European country – Sweden – has an industry-run, centralised disclosure database of
37 payments to patient organisations,⁵⁶ and there is no reason why the ABPI should not have
38 the same.
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44 Given the shortcomings of the industry self-regulatory system, charity regulators should
45 introduce tailored solutions related to reporting corporate funding in annual accounts,
46 including a standardised template comprising a short payment description (including
47 payment form and goal), its value, and donor name. Patient organisation websites should
48 report this information separately or include clear signposting to the annual accounts. A key
49 step in refining these solutions would involve in-depth exploration of perspectives of patient
50 organisations. However, ultimately, only a single state-run permanent database integrating
51 payments reported by drug companies and patient organisations could eliminate
52 underreporting.
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Figure 1

The Venn Diagram illustrates the relationships between the measures of payment underreporting employed in this paper by showing the overlap between the industry and patient organization datasets. Please note that the size of specific parts of the diagram does not reflect the size of either of the datasets or the overlap between them. All outcome measures were reported for the number and value of payments.

Figure 2

The bars in Figure 2A-1B show the number of donors with varying level of overlap between their recipient lists and patient organisation data based on the number (Figure 2A) and value (Figure 2B) of payments. For example, based on the number of payments there were 13 companies with 20-29.9% recipients also being reported in patient organisation data (Figure 2A).

The bars in Figures 2C-1D show the number of recipients with varying level of overlap between their donor lists and industry data based on the number (Figure 2C) and value (Figure 2D) of payments. For example, based on the number of payments there were 24 recipients with 50-59.9% of donors also being reported in industry data.

Contributors

PO conceived and designed the study, managed, analysed and interpreted the data, as well as drafted the article MC analysed the data and drafted the article. ER collected and managed the data, and drafted the article. SM designed the study, contributed to interpretation, drafted the article

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Shai Mulinari and Piotr Ozieranski's work on this study was supported by the grant "What can be learnt from the new pharmaceutical industry payment disclosures?" awarded by the Swedish Research Council for Health, Working Life and Welfare (FORTE #2016-00875). Emily Rickard's work was funded through the above grant. Marcell Csanadi did not receive funding for this work.

Details of the role of study sponsors

The funding body has played no part in the design or conduct of this study

Statement of independence of researchers from funders

All researchers working on this study are independent from the funding body.

Competing interests

We have read and understood the BMJ Group policy on declaration of interests and declare the following interests:

Shai Mulinari and Piotr Ozieranski's work on the study reported in this paper was supported by the grant "What can be learnt from the new pharmaceutical industry payment disclosures?" awarded by the Swedish Research Council for Health, Working Life and Welfare (FORTE #2016-00875). Emily Rickard's work was funded through the above grant. Marcell Csanadi did not receive funding for this work. We have no other competing interests to declare.

Patient consent

None required.

Ethical approval

No ethical approval was needed. The ethical implications of this study article were approved via a peer ethics review process at the Department of Social and Policy Sciences, University of Bath in April 2016. This study did not require a full ethical approval as it relied on publicly available data aggregated at the organisational level

Data sharing

The authors of this study agree to share data underpinning this study in the form of web supplements 3-20 available from the University of Bath Research Data Archive. The raw data poses no risk to anonymity of individuals as it draws on publicly available reports concerning financial transfers between organisations.

The reference for this dataset is: Ozieranski, P., Csanadi, M., Rickard, E., Mulinari, S., 2020. *Underreporting of drug industry payments to patient organisations in the UK (2012-2016)*. Bath: University of Bath Research Data Archive. <https://doi.org/10.15125/BATH-00784>

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Transparency declaration

The guarantor (Piotr Ozieranski) affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

1 Figure 1: Relationships between the outcome measures of underreporting of drug company
 2 payments in industry and patient organisation data
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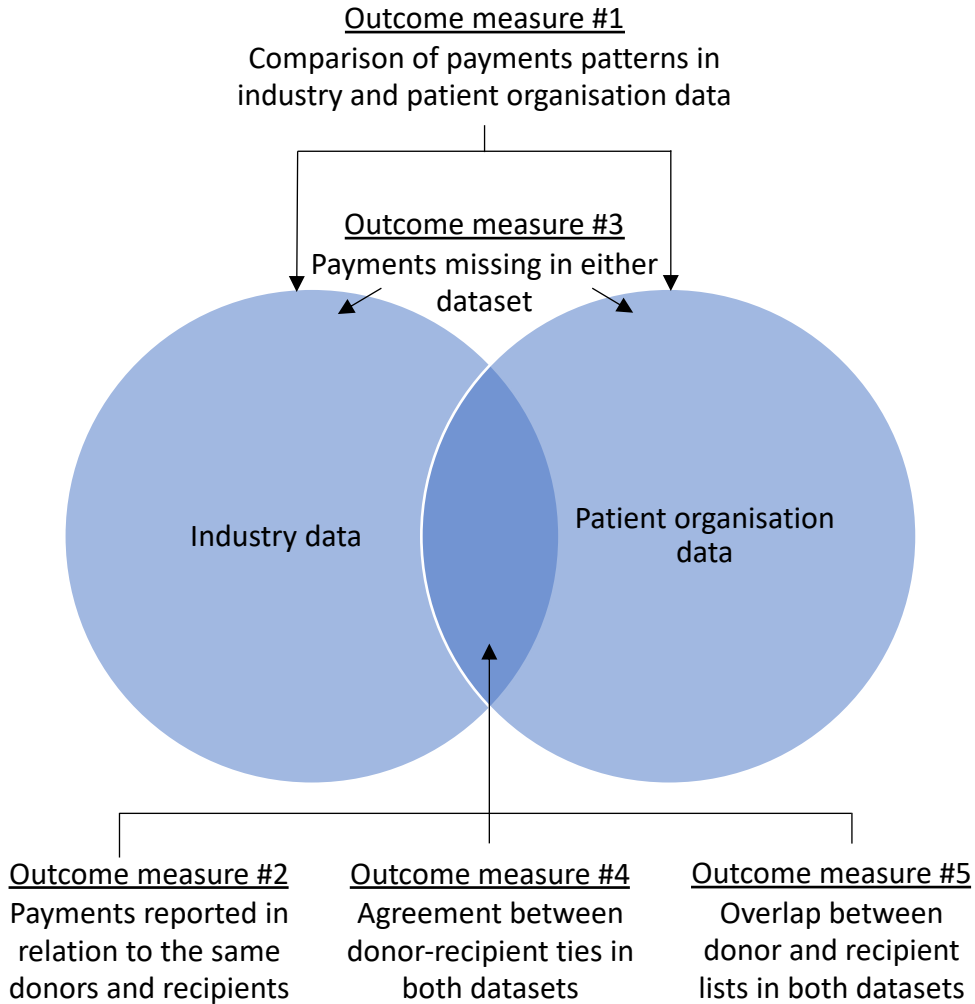


Figure 2A:
Overlap between recipient lists and patient organisation data
- Based on the *number of payments*

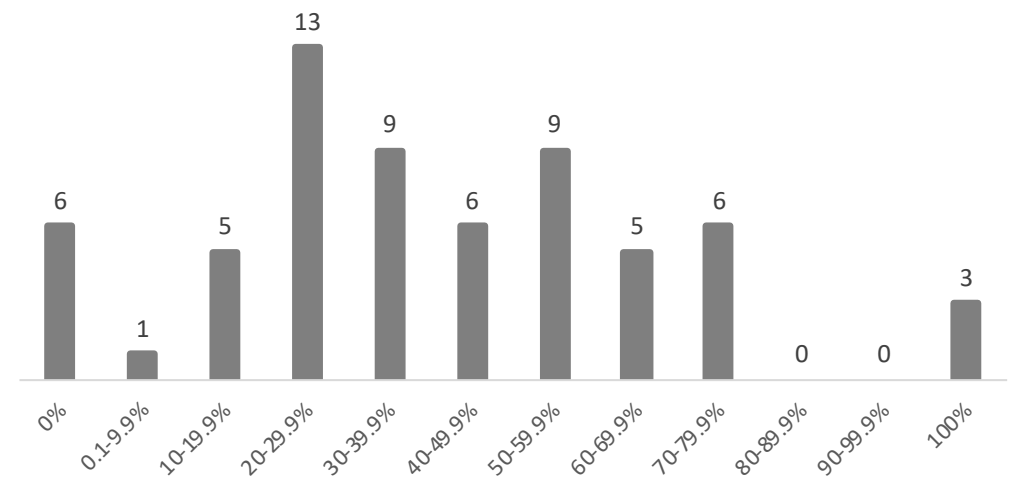


Figure 2B:
Overlap between recipient lists and patient organisation data
Based on the *value of payments*

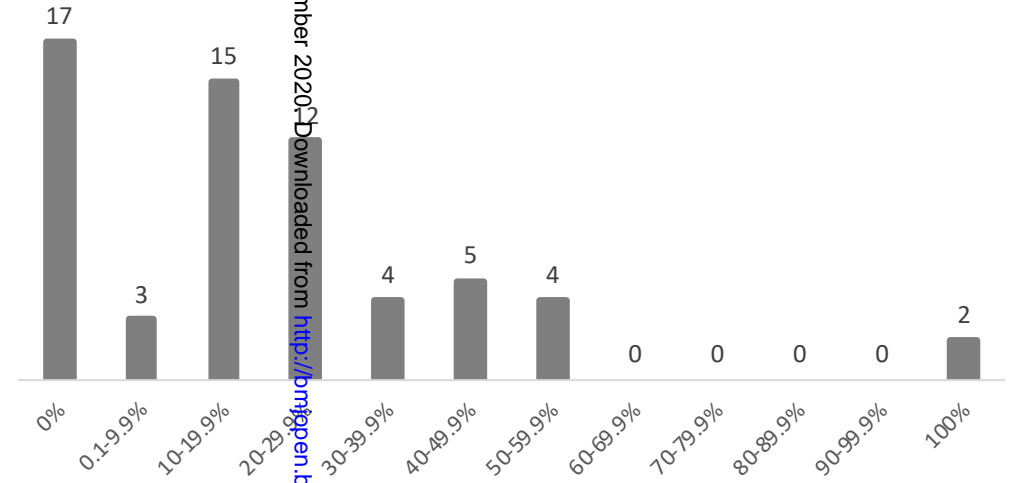


Figure 2C:
Overlap between donors lists and industry data - Based on
the *number of payments*

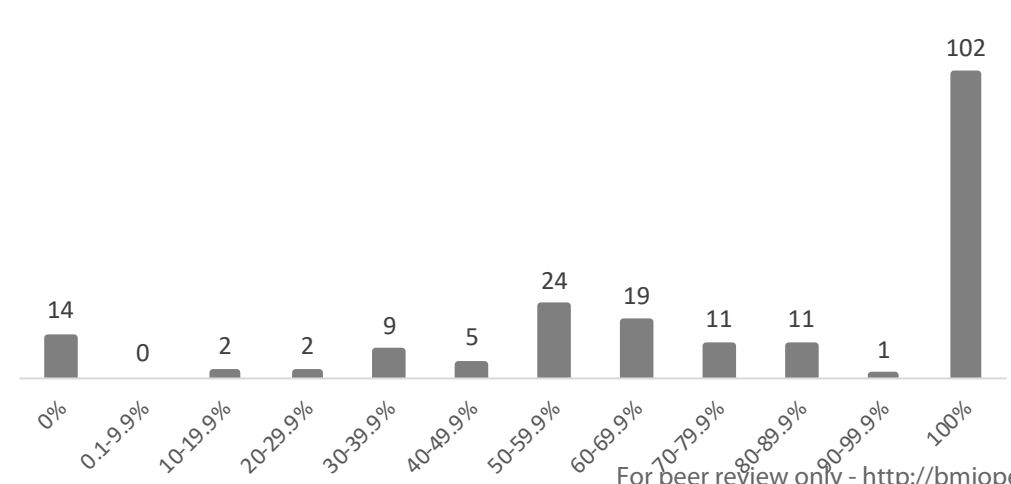
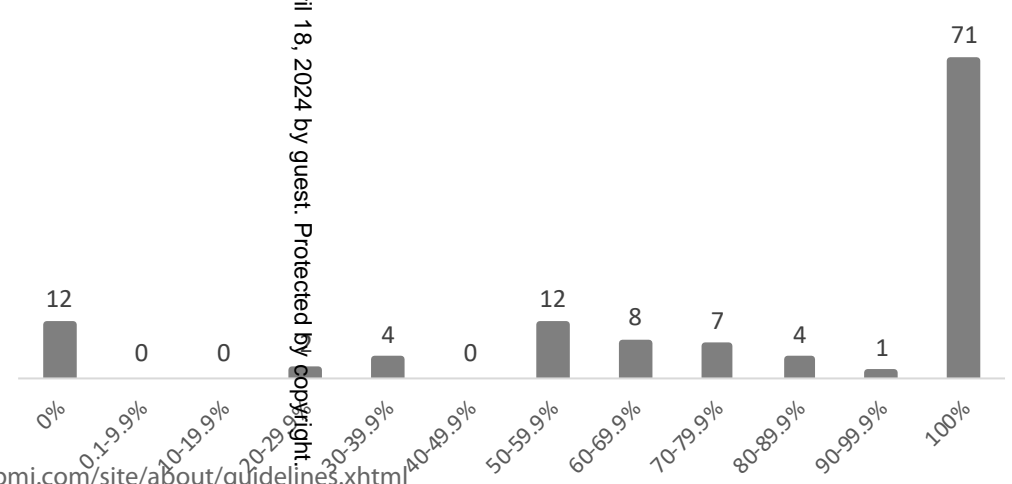
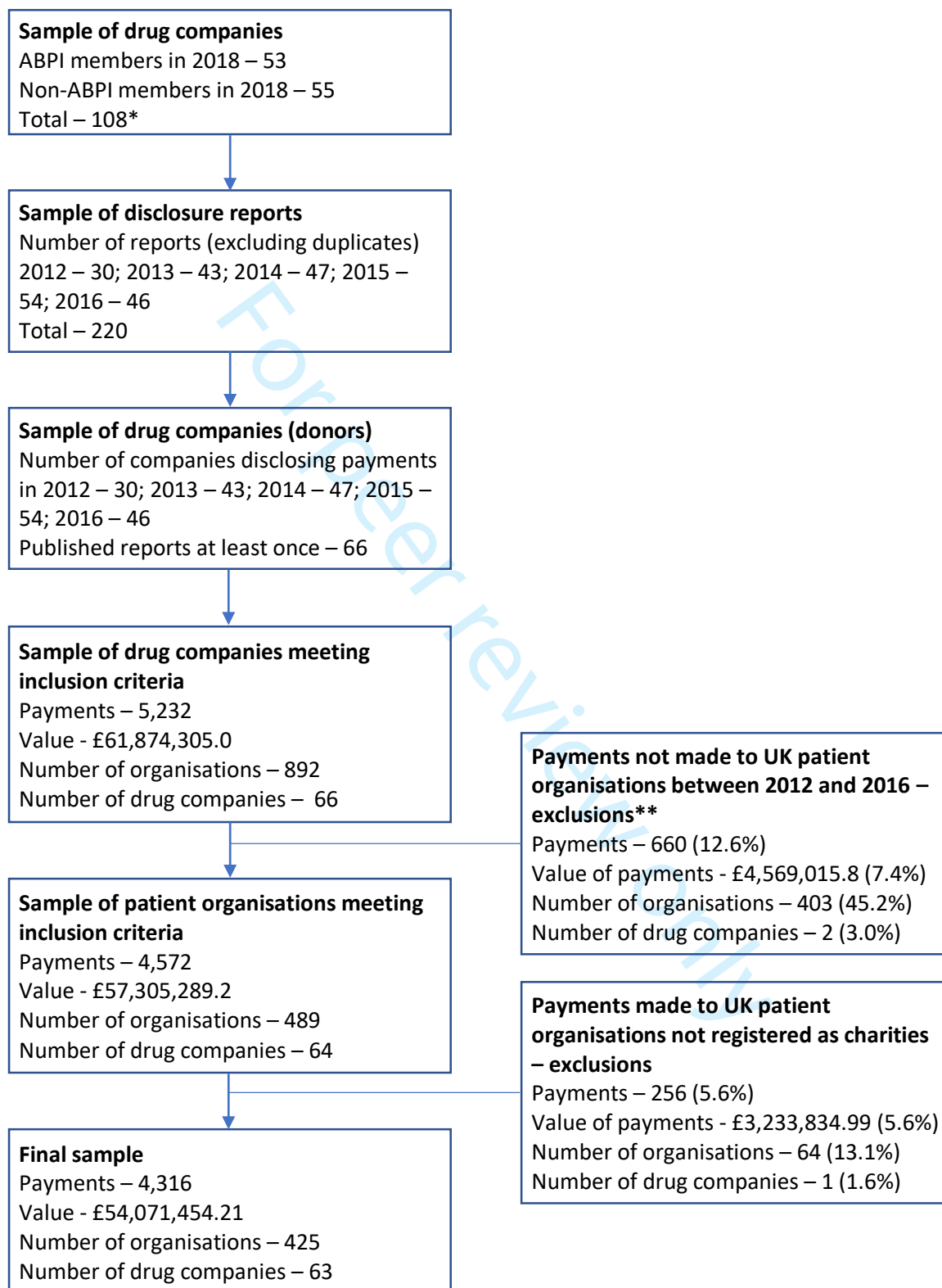


Figure 2D:
Overlap between donors lists and industry data - Based on
the *value of payments*



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Web supplement 1 – Research process: pharmaceutical industry data



*Complete lists of companies provided in Table 1

**Detailed breakdown provided in Table 2

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

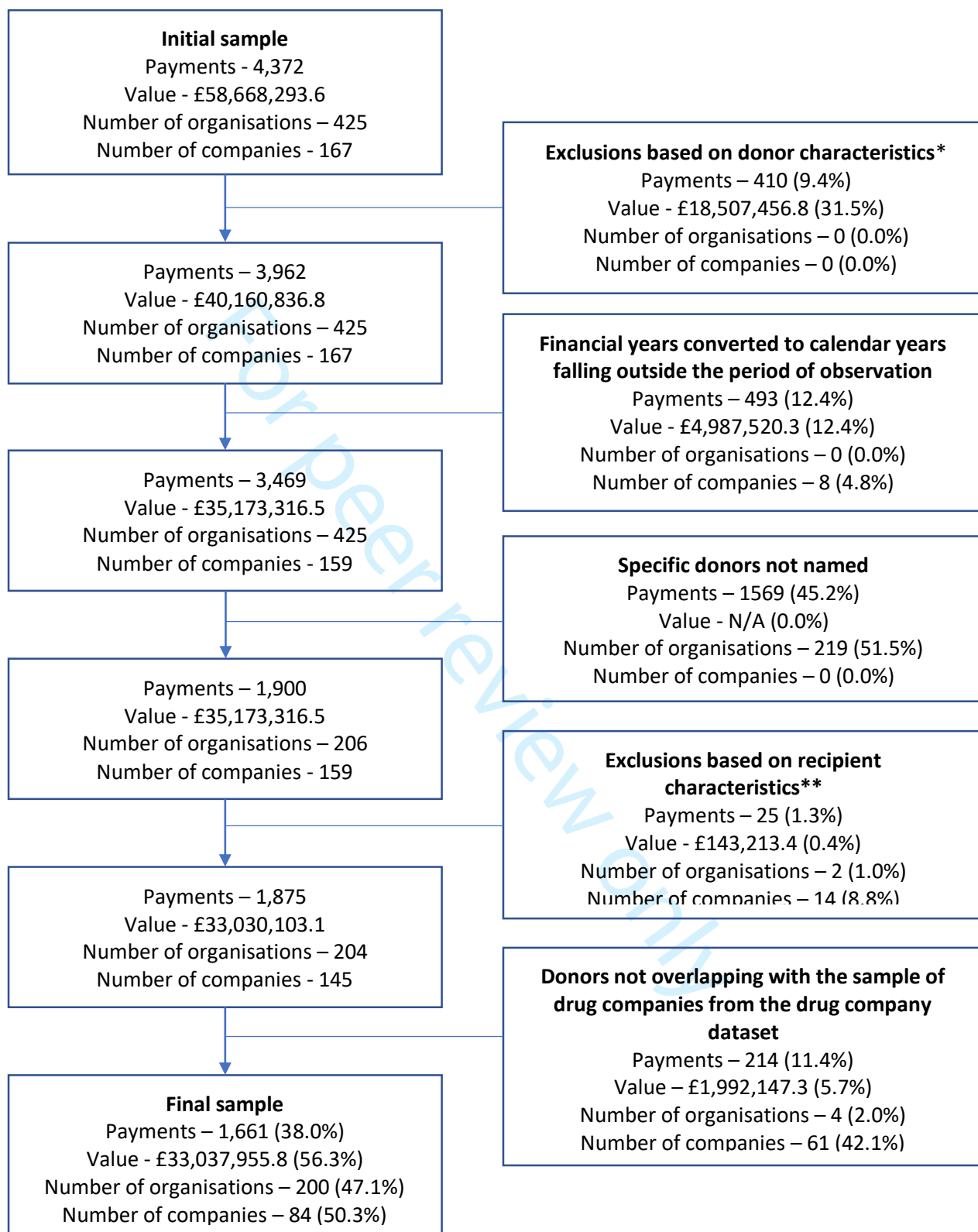
| ABPI member in 2018 – n=53 | Non-ABPI member in 2018 – n=55 |
|----------------------------|--------------------------------|
| A. Menarini | Accretio |
| Abbvie | Actavis |
| Actelion | Aegerion |
| Alexion | Aguettant |
| Alimera Sciences | Alcon |
| ALK-Abelo | AMCo |
| Allergan | ApoPharma |
| 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 UK organisation | 54 (8.2) | 716,044.0 (15.7) | 30 (7.4) |
| <i>Excluded UK organisations</i> | | | |
| 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) |

Web supplement 2 Research process: patient organisation data



*More detailed breakdown in Table 3

**More detailed breakdown in Table 4

Table 3 Exclusions based on donor characteristics – detailed breakdown

| Reason for exclusion | Number of Payments excluded | Value of payments excluded (£) |
|---|-----------------------------|--------------------------------|
| <i>Exclusions unique to patient organisation dataset</i> | | |
| Regional branch (same charity number as national branch) | 229 | 13,213,514.2 |
| Subsumed under a larger organisation (same charity number as larger organisation) | 125 | 291,862.9 |
| Years before merger | 14 | 1,515.0 |
| Years after merger | 9 | - |
| <i>Exclusions resulting from exclusions in drug company dataset</i> | | |
| Third sector - healthcare provider | 6 | - |
| Third sector - professional organisation | 6 | - |
| Third sector - not focusing directly on health | 15 | 5,000,564.8 |
| Not a charity | 6 | - |
| Total | 410 | 18,507,456.8 |

Table 4 Exclusions based on recipient characteristics – detailed breakdown

| | Number of Payments excluded | Value of payments excluded (£) | Number of drug companies excluded | Number of patient organisations excluded |
|------------------------------|-----------------------------|--------------------------------|-----------------------------------|--|
| More than one organisation | 8 | 58,485.5 | 7 | 0 |
| Not a pharmaceutical company | 17 | 84,727.8 | 7 | 2 |
| Total | 25 | 143,213.4 | 14 | 2 |

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This online dataset comprises web supplements (WS) accompanying the paper entitled “An underreported re

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Web Supplement 3. Donors - Absolute and relative differences in the number and value of payments (all ye**NUMBER OF PAYMENTS**

Number of payments - industry data

Number of payments - patient organisation data

Number of drug companies with at least one payment - industry data

Number of drug companies with at least one payment - patient organisation data

NUMBER OF PAYMENTS - THRESHOLDS

Threshold 0: Number of drug companies with at least 1 one payment in at least one dataset (1 if condition m

Threshold 1: Number of drug companies with more than 1 one payment in at least one dataset (1 if condition

Threshold 2: Number of drug companies with more than 10 payments in at least one dataset (1 if condition n

Threshold 3: Number of drug companies with more than 100 payments in at least one dataset (1 if condition

NUMBER OF PAYMENTS - ABSOLUTE DIFFERENCES**Number of payments - threshold 0**

Number of drug companies with exact match in both datasets

Number of drug companies with more payments t in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

Number of payments - threshold 1

Number of drug companies with exact match in both datasets

Number of drug companies with more payments t in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

Number of payments - threshold 2

Number of drug companies with exact match in both datasets

Number of drug companies with more payments t in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

Number of payments - threshold 3

Number of drug companies with exact match in both datasets

Number of drug companies with more payments t in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i
 Highest absolute difference between patient organisation and industry data - number of payments higher in j

NUMBER OF PAYMENTS - RELATIVE DIFFERENCES

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 1

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 2

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 3

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES

Value of payments - industry data (2016 £)
 Value of payments - patient organisation data (2016 £)
 Number of payments with value >£0 - industry data
 Number of payments with value >£0 - patient organisation data
 Number of drug companies with at least one payment with the value >£0 - industry data
 Number of drug companies with at least one payment with the value >£0 - patient organisation data

VALUE OF PAYMENTS - THRESHOLDS

Threshold 1: Number of drug companies with at least one payment with value >£0 in at least one dataset (1 if
 Threshold 2: Number of drug companies with payments with the value of more than £10,000 in at least one c
 Threshold 3: Number of drug companies with payments with the value of more than £100,000 in at least one

VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES

Number of payments - threshold 1

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2 Number of drug companies with exact match in both datasets
3 Number of drug companies with higher payment value in industry data
4 Number of drug companies with higher payment value in patient organisation data
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8 Highest absolute difference between patient organisation and industry data - number of payments higher in i
9 Highest absolute difference between patient organisation and industry data - number of payments higher in i
10

Number of payments - threshold 2

11
12 Number of drug companies with exact match in both datasets
13 Number of drug companies with higher payment value in industry data
14 Number of drug companies with higher payment value in patient organisation data
15
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18
19 Highest absolute difference between patient organisation and industry data - number of payments higher in i
20 Highest absolute difference between patient organisation and industry data - number of payments higher in i
21
22

Number of payments - threshold 3

23
24 Number of drug companies with exact match in both datasets
25 Number of drug companies with higher payment value in industry data
26 Number of drug companies with higher payment value in patient organisation data
27
28

29
30 Highest absolute difference between patient organisation and industry data - number of payments higher in i
31 Highest absolute difference between patient organisation and industry data - number of payments higher in i
32
33

VALUE OF PAYMENTS - RELATIVE DIFFERENCES

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37 Relative difference <10%
38 Relative difference <20%
39 Relative difference <50%
40 Relative difference = 100%
41
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Number of payments - threshold 1

43
44 Relative difference <10%
45 Relative difference <20%
46 Relative difference <50%
47 Relative difference = 100%
48
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Number of payments - threshold 2

50
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52 Relative difference <10%
53 Relative difference <20%
54 Relative difference <50%
55 Relative difference = 100%
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Number of payments - threshold 3

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59 Relative difference <10%
60 Relative difference <20%

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3 Relative difference = 100%
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| | | A. Menarini | Abbvie | Actavis | Actelion |
|--|--------|-------------|--------|---------|----------|
| Total | | 1 | 1 | 0 | 1 |
| 4316 | | 3 | 281 | 5 | 38 |
| 1661 | | 0 | 84 | 5 | 23 |
| 63 | | 1 | 1 | 1 | 1 |
| 84 | | 0 | 1 | 1 | 1 |
| Number of drug c % of all drug companies with at least one payment in at least one dataset | | | | | |
| 87 | 100.0% | 1 | 1 | 1 | 1 |
| 80 | 92.0% | 1 | 1 | 1 | 1 |
| 47 | 54.0% | | 1 | | 1 |
| 10 | 11.5% | | 1 | | |
| Number of drug c % of all drug companies at a given threshold | | | | | |
| 3 | 3.4% | | | 1 | |
| 49 | 56.3% | 1 | 1 | | 1 |
| 35 | 40.2% | | | | |
| Number of payments | | | | | |
| 757 | | 3 | 197 | | 15 |
| 53 | | | | | |
| Number of drug c % of all drug companies at a given threshold | | | | | |
| 3 | 3.8% | | | 1 | |
| 49 | 61.3% | 1 | 1 | | 1 |
| 28 | 35.0% | | | | |
| Number of payments | | | | | |
| 757 | | 3 | 197 | | 15 |
| 53 | | | | | |
| Number of drug c % of all drug companies at a given threshold | | | | | |
| 1 | 2.1% | | | | |
| 36 | 76.6% | | 1 | | 1 |
| 10 | 21.3% | | | | |
| Number of payments | | | | | |
| 757 | | | 197 | | 15 |
| 53 | | | | | |
| Number of drug c % of all drug companies at a given threshold | | | | | |
| 0 | 0.0% | | | | |
| 10 | 100.0% | | 1 | | |

| | | | | | | |
|----|---|-------|----------|-------------|----------|-----------|
| 1 | | | | | | |
| 2 | 0 | 0.0% | | | | |
| 3 | | | | | | |
| 4 | Number of payments | | | | | |
| 5 | 757 | | 197 | | | |
| 6 | 0 | | | | | |
| 7 | | | | | | |
| 8 | | | | | | |
| 9 | | | | | | |
| 10 | Number of drug c % of all drug companies | | | | | |
| 11 | 5 | 5.7% | | 0.0% | | |
| 12 | 9 | 10.3% | | 0.0% | | |
| 13 | 21 | 24.1% | | 0.0% | 39.5% | |
| 14 | 27 | 31.0% | 100.0% | | | |
| 15 | | | | | | |
| 16 | | | | | | |
| 17 | | | | | | |
| 18 | Number of drug c % of all companies at a given threshold | | | | | |
| 19 | 5 | 6.3% | | 0.0% | | |
| 20 | 9 | 11.3% | | 0.0% | | |
| 21 | 21 | 26.3% | | 0.0% | 39.5% | |
| 22 | 20 | 25.0% | 100.0% | | | |
| 23 | | | | | | |
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| 25 | Number of drug c % of all companies at a given threshold | | | | | |
| 26 | 3 | 6.4% | | | | |
| 27 | 5 | 10.6% | | | | |
| 28 | 15 | 31.9% | | | 39.5% | |
| 29 | 2 | 4.3% | | | | |
| 30 | | | | | | |
| 31 | | | | | | |
| 32 | | | | | | |
| 33 | Number of drug c % of all companies at a given threshold | | | | | |
| 34 | 0 | 0.0% | | | | |
| 35 | 0 | 0.0% | | | | |
| 36 | 1 | 10.0% | | | | |
| 37 | 0 | 0.0% | | | | |
| 38 | | | | | | |
| 39 | | | | | | |
| 40 | | | | | | |
| 41 | | | | | | |
| 42 | Total | | | | | |
| 43 | £54,071,454.2 | | 33,907.5 | 3,584,604.6 | 49,000.0 | 364,970.8 |
| 44 | £33,037,955.8 | | - | 1,412,340.9 | 49,240.0 | 217,382.1 |
| 45 | 4235 | | 3 | 281 | 5 | 38 |
| 46 | 772 | | 0 | 40 | 2 | 16 |
| 47 | 62 | | 1 | 1 | 1 | 1 |
| 48 | 62 | | 0 | 1 | 1 | 1 |
| 49 | | | | | | |
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| 53 | Number of drug c % of all drug companies with at least one payment with the value of at least | | | | | |
| 54 | 74 | 85.1% | 1 | 1 | 1 | 1 |
| 55 | 45 | 51.7% | | 1 | | 1 |
| 56 | 17 | 19.5% | | 1 | | |
| 57 | | | | | | |
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| 60 | Number of drug c % of all drug companies at a given threshold | | | | | |

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|---|----|-------|--------|---------|------|--------|
| | 0 | 0.0% | | | | |
| | 48 | 64.9% | 1 | 1 | | 1 |
| | 26 | 35.1% | | | 1 | |
| Vallue of payments | | | | | | |
| 6,406,351.1 | | | 33908 | 2172264 | | 147589 |
| 2,960,716.0 | | | | | 240 | |
| Number of drug c % of all drug companies at a given threshold | | | | | | |
| | 0 | 0.0% | | | | |
| | 32 | 71.1% | | 1 | | 1 |
| | 13 | 28.9% | | | | |
| Vallue of payments | | | | | | |
| 6,406,351.1 | | | | 2172264 | | 147589 |
| 2,960,716.0 | | | | | | |
| Number of drug c % of all drug companies at a given threshold | | | | | | |
| | 0 | 0.0% | | | | |
| | 13 | 76.5% | | 1 | | |
| | 4 | 23.5% | | | | |
| Vallue of payments | | | | 0 | | |
| 6,406,351.1 | | | | 2172264 | | |
| 2,960,716.0 | | | | | | |
| Number of drug c % of all drug companies with at least one payment with value >£0 in at lea | | | | | | |
| | 3 | 4.1% | | | 0.5% | |
| | 9 | 12.2% | | | 0.5% | |
| | 14 | 18.9% | | | 0.5% | 40.4% |
| | 24 | 32.4% | 100.0% | | | |
| Number of drug c % of all drug companies at a given threshold | | | | | | |
| | 3 | 4.1% | | | 0.5% | |
| | 9 | 12.2% | | | 0.5% | |
| | 14 | 18.9% | | | 0.5% | 40.4% |
| | 24 | 32.4% | 100.0% | | | |
| Number of drug c % of all drug companies at a given threshold | | | | | | |
| | 1 | 2.2% | | | | |
| | 5 | 11.1% | | | | |
| | 9 | 20.0% | | | | 40.4% |
| | 4 | 8.9% | | | | |
| Number of drug c % of all drug companies at a given threshold | | | | | | |
| | 0 | 0.0% | | | | |
| | 2 | 11.8% | | | | |

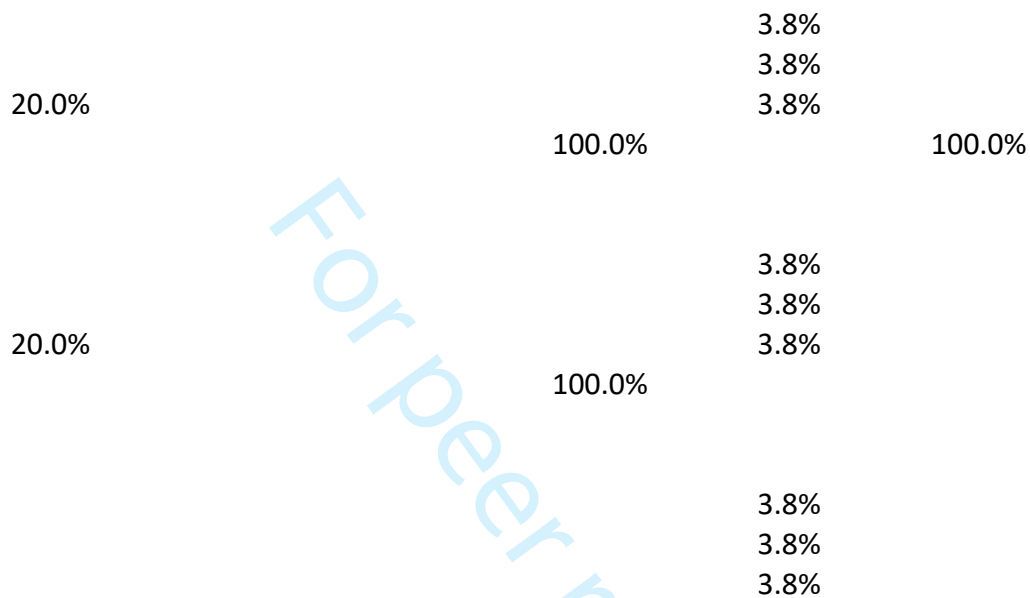
| | | |
|----|---|-------|
| 1 | | |
| 2 | 2 | 11.8% |
| 3 | 1 | 5.9% |
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| - | 83,733.8 | 70,583.4 | - | 148,240.9 | - | - |
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| 8,728.1 | 3,461,815.7 | - | 148,100.2 | - | 376,373.5 |
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| - | 1,750,167.8 | - | 173,152.9 | 102,297.0 | 5,195,484.0 |
| 5,070.3 | 837,180.0 | - | 82,633.4 | 33,700.5 | 2,102,441.4 |
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| 43 | 753,861.7 | 5,276.0 | 49,682.0 | - | 184,272.2 | 9,304,016.7 |
| 44 | 49,315.6 | 435,156.4 | - | 1,028.5 | 88,840.6 | 10,713,090.3 |
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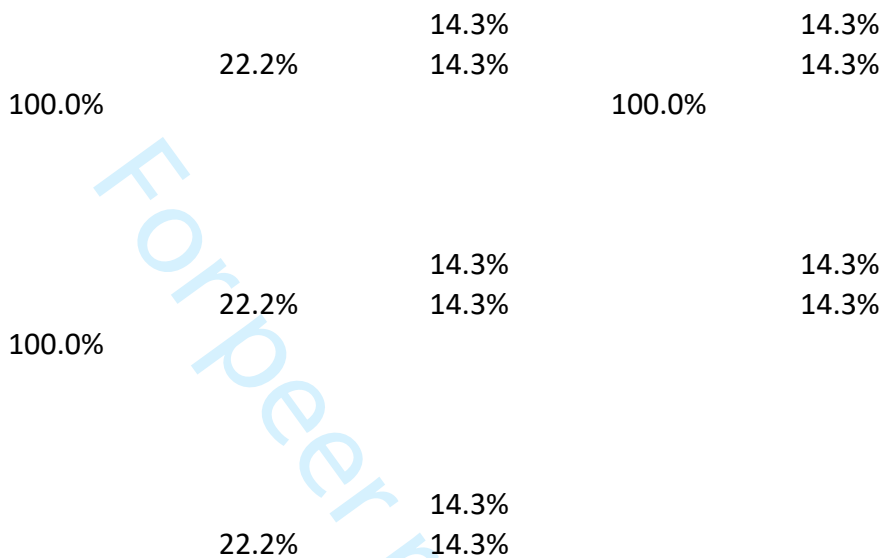
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| 11,110.0 | - | 6,614,214.3 | 642,199.4 | - | 48,612.7 |
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Web Supplement 4. Donors - Absolute and relative differences in the number and value of payments (individually)**NUMBER OF PAYMENTS - ABSOLUTE DIFFERENCES****Threshold 0: At least 1 one payment in at least one dataset**

Total

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in industry data

Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data

Threshold 1: More than 1 one payment in at least one dataset

Total

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in industry data

Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data

Threshold 2: More than 10 payments in at least one dataset

Total

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in industry data

Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data

Threshold 3: More than 100 payments in at least one dataset

Total

Number of drug companies with exact match in both datasets

Number of drug companies with more payments in industry data

Number of drug companies with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in industry data

Highest absolute difference between patient organisation and industry data - number of payments higher in patient organisation data

NUMBER OF PAYMENTS - RELATIVE DIFFERENCES**Threshold 0: At least 1 one payment in at least one dataset**

Total

Relative difference <10%

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2 Relative difference <20%
3 Relative difference <50%
4 Relative difference = 100%

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7 **Threshold 1: More than 1 one payment in at least one dataset**

8 Total
9 Relative difference <10%
10 Relative difference <20%
11 Relative difference <50%
12 Relative difference = 100%

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15 **Threshold 2: More than 10 payments in at least one dataset**

16 Total
17 Relative difference <10%
18 Relative difference <20%
19 Relative difference <50%
20 Relative difference = 100%

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23 **Threshold 3: More than 100 payments in at least one dataset**

24 Total
25 Relative difference <10%
26 Relative difference <20%
27 Relative difference <50%
28 Relative difference = 100%

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33 **VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES**

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35 **Threshold 1: At least one payment with value >£0 in at least one dataset**

36 Total
37 Number of drug companies with exact match in both datasets
38 Number of drug companies with higher payment value in industry data
39 Number of drug companies with higher payment value in patient organisation data

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44 Highest absolute difference between patient organisation and industry data - number of payments higher in i
45 Highest absolute difference between patient organisation and industry data - number of payments higher in j

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48 **Threshold 2: Payments with the value of more than £10,000 in at least one dataset**

49 Total
50 Number of drug companies with exact match in both datasets
51 Number of drug companies with higher payment value in industry data
52 Number of drug companies with higher payment value in patient organisation data

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57 Highest absolute difference between patient organisation and industry data - number of payments higher in i
58 Highest absolute difference between patient organisation and industry data - number of payments higher in j

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60 **Threshold 3: Payments with the value of more than £100,000 in at least one dataset**

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3 Number of drug companies with exact match in both datasets

4 Number of drug companies with higher payment value in industry data

5 Number of drug companies with higher payment value in patient organisation data
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9 Highest absolute difference between patient organisation and industry data - number of payments higher in i

10 Highest absolute difference between patient organisation and industry data - number of payments higher in j
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13 VALUE OF PAYMENTS- RELATIVE DIFFERENCES

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15 **Threshold 1: At least one payment with value >£0 in at least one dataset**

16 Total

17 Relative difference <10%

18 Relative difference <20%

19 Relative difference <50%

20 Relative difference = 100%
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24 **Threshold 2: Payments with the value of at least £10,000 in at least one dataset**

25 Total

26 Relative difference <10%

27 Relative difference <20%

28 Relative difference <50%

29 Relative difference = 100%
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33 **Threshold 3: Payments with the value of at least 100,000 in at least one dataset**

34 Total

35 Relative difference <10%

36 Relative difference <20%

37 Relative difference <50%

38 Relative difference = 100%
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| 87 | 100.0% | 61 | 100.0% | 68 | 100.0% |
| 3 | 3.4% | 1 | 1.6% | 7 | 10.3% |
| 49 | 56.3% | 28 | 45.9% | 28 | 41.2% |
| 35 | 40.2% | 32 | 52.5% | 33 | 48.5% |
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| 757 | | 216 | | 135 | |
| 53 | | 18 | | 16 | |
| Number of drug c | % of all drug 0 | Number of drug | % of all drug 0 | Number of dr | % of all drug 0 |
| 80 | 100.0% | 46 | 100.0% | 55 | 100.0% |
| 3 | 3.8% | 1 | 2.2% | 3 | 5.5% |
| 49 | 61.3% | 28 | 60.9% | 27 | 49.1% |
| 28 | 35.0% | 17 | 37.0% | 25 | 45.5% |
| Number of payments | | Number of payments | | Number of payments | |
| 757 | | 216 | | 135 | |
| 53 | | 18 | | 16 | |
| Number of drug c | % of all drug 0 | Number of drug | % of all drug 0 | Number of dr | % of all drug 0 |
| 47 | 100.0% | 16 | 100.0% | 17 | 100.0% |
| 1 | 2.1% | 0 | 0.0% | 0 | 0.0% |
| 36 | 76.6% | 13 | 81.3% | 14 | 82.4% |
| 10 | 21.3% | 3 | 18.8% | 3 | 17.6% |
| Number of payments | | Number of payments | | Number of payments | |
| 757 | | 216 | | 135 | |
| 53 | | 18 | | 16 | |
| Number of drug c | % of all drug 0 | Number of drug | % of all drug 0 | Number of dr | % of all drug 0 |
| 10 | 100.0% | 1 | 100.0% | 1 | 100.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 10 | 100.0% | 1 | 100.0% | 1 | 100.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| Number of payments | | Number of payments | | Number of payments | |
| 757 | | 216 | | 135 | |
| 0 | | 0 | | 0 | |
| Number of drug c | % of all drug co | Number of drug | % of all drug co | Number of dr | % of all drug cc |
| 87 | 100.0% | 61 | 100.0% | 68 | 100.0% |
| 5 | 5.7% | 1 | 1.6% | 7 | 10.3% |

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|-------------------|---------------|--------|-------------------|---------------|-------------------|--------------|---------------|---|
| | 9 | 10.3% | 2 | 3.3% | 7 | 10.3% | | |
| | 21 | 24.1% | 7 | 11.5% | 10 | 14.7% | | |
| | 27 | 31.0% | 36 | 59.0% | 33 | 48.5% | | |
| Number of drug c | % of all drug | 0 | Number of drug | % of all drug | 0 | Number of dr | % of all drug | 0 |
| | 80 | 100.0% | 46 | 100.0% | 55 | 100.0% | | |
| | 5 | 6.3% | 1 | 2.2% | 3 | 5.5% | | |
| | 9 | 11.3% | 2 | 4.3% | 3 | 5.5% | | |
| | 21 | 26.3% | 7 | 15.2% | 6 | 10.9% | | |
| | 20 | 25.0% | 21 | 45.7% | 24 | 43.6% | | |
| Number of drug c | % of all drug | 0 | Number of drug | % of all drug | 0 | Number of dr | % of all drug | 0 |
| | 47 | 100.0% | 16 | 100.0% | 17 | 100.0% | | |
| | 3 | 6.4% | 0 | 0.0% | 0 | 0.0% | | |
| | 5 | 10.6% | 0 | 0.0% | 0 | 0.0% | | |
| | 15 | 31.9% | 1 | 6.3% | 0 | 0.0% | | |
| | 2 | 4.3% | 3 | 18.8% | 3 | 17.6% | | |
| Number of drug c | % of all drug | 0 | Number of drug | % of all drug | 0 | Number of dr | % of all drug | 0 |
| | 10 | 100.0% | 1 | 100.0% | 1 | 100.0% | | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | | |
| | 1 | 10.0% | 0 | 0.0% | 0 | 0.0% | | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | | |
| Number of drug c | % of all drug | 0 | Number of drug | % of all drug | 0 | Number of dr | % of all drug | 0 |
| | 74 | 100.0% | 52 | 100.0% | 56 | 100.0% | | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | | |
| | 48 | 64.9% | 26 | 50.0% | 35 | 62.5% | | |
| | 26 | 35.1% | 26 | 50.0% | 21 | 37.5% | | |
| Value of payments | | | Value of payments | | Value of payments | | | |
| | 6,406,351.2 | | 1,576,293.48 | | 666,171.11 | | | |
| | 2,960,716.0 | | 501,114.66 | | 851,009.34 | | | |
| Number of drug c | % of all drug | 0 | Number of drug | % of all drug | 0 | Number of dr | % of all drug | 0 |
| | 45 | 100.0% | 20 | 100.0% | 24 | 100.0% | | |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | | |
| | 32 | 71.1% | 13 | 65.0% | 14 | 58.3% | | |
| | 13 | 28.9% | 7 | 35.0% | 10 | 41.7% | | |
| Value of payments | | | Value of payments | | Value of payments | | | |
| | 6,406,351.2 | | 1,576,293.5 | | 666,171.1 | | | |
| | 2,960,716.0 | | 501,114.7 | | 851,009.3 | | | |
| Number of drug c | % of all drug | 0 | Number of drug | % of all drug | 0 | Number of dr | % of all drug | 0 |

| | | | | | | |
|----|----------------------------------|--------|----------------------------------|--------|------------------------------|--------|
| 1 | | | | | | |
| 2 | 17 | 100.0% | 2 | 100.0% | 1 | 100.0% |
| 3 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 4 | 13 | 76.5% | 2 | 100.0% | 1 | 100.0% |
| 5 | 4 | 23.5% | 0 | 0.0% | 0 | 0.0% |
| 6 | | | | | | |
| 7 | | | | | | |
| 8 | Value of payments | | Value of payments | | Value of payments | |
| 9 | 6,406,351.2 | | 1,576,293.5 | | 604,556.0 | |
| 10 | 2,960,716.0 | | - | | - | |
| 11 | | | | | | |
| 12 | | | | | | |
| 13 | | | | | | |
| 14 | | | | | | |
| 15 | Number of drug c % of all drug 0 | | Number of drug ξ % of all drug 0 | | Number of dr % of all drug 0 | |
| 16 | 74 | 100.0% | 52 | 100.0% | 56 | 100.0% |
| 17 | 3 | 4.1% | 1 | 1.9% | 0 | 0.0% |
| 18 | 9 | 12.2% | 1 | 1.9% | 4 | 7.1% |
| 19 | 14 | 18.9% | 4 | 7.7% | 7 | 12.5% |
| 20 | 24 | 32.4% | 32 | 61.5% | 30 | 53.6% |
| 21 | | | | | | |
| 22 | | | | | | |
| 23 | | | | | | |
| 24 | Number of drug c % of all drug 0 | | Number of drug ξ % of all drug 0 | | Number of dr % of all drug 0 | |
| 25 | 45 | 100.0% | 20 | 100.0% | 24 | 100.0% |
| 26 | 1 | 2.2% | 0 | 0.0% | 0 | 0.0% |
| 27 | 5 | 11.1% | 0 | 0.0% | 1 | 4.2% |
| 28 | 9 | 20.0% | 1 | 5.0% | 3 | 12.5% |
| 29 | 4 | 8.9% | 8 | 40.0% | 9 | 37.5% |
| 30 | | | | | | |
| 31 | | | | | | |
| 32 | | | | | | |
| 33 | Number of drug c % of all drug 0 | | Number of drug ξ % of all drug 0 | | Number of dr % of all drug 0 | |
| 34 | 17 | 100.0% | 2 | 100.0% | 1 | 100.0% |
| 35 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 36 | 2 | 11.8% | 0 | 0.0% | 0 | 0.0% |
| 37 | 2 | 11.8% | 0 | 0.0% | 1 | 100.0% |
| 38 | 1 | 5.9% | 0 | 0.0% | 0 | 0.0% |
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| 60 | | | | | | |

| | 2014 | | 2015 | | 2016 | |
|--------------------|------|---------------|--------------------|---------------|--------------------|---------------|
| Number of drug | | % of all drug | Number of drug | % of all drug | Number of drug | % of all drug |
| | 72 | 100.0% | 74 | 100.0% | 69 | 100.0% |
| | 4 | 5.6% | 7 | 9.5% | 4 | 5.8% |
| | 38 | 52.8% | 42 | 56.8% | 39 | 56.5% |
| | 30 | 41.7% | 25 | 33.8% | 26 | 37.7% |
| Number of payments | | | Number of payments | | Number of payments | |
| | 108 | | 125 | | 173 | |
| | 13 | | 13 | | 12 | |
| Number of drug | | % of all drug | Number of drug | % of all drug | Number of drug | % of all drug |
| | 55 | 100.0% | 57 | 100.0% | 50 | 100.0% |
| | 1 | 1.8% | 5 | 8.8% | 3 | 6.0% |
| | 36 | 65.5% | 42 | 73.7% | 38 | 76.0% |
| | 18 | 32.7% | 10 | 17.5% | 9 | 18.0% |
| Number of payments | | | Number of payments | | Number of payments | |
| | 108 | | 125 | | 173 | |
| | 13 | | 13 | | 12 | |
| Number of drug | | % of all drug | Number of drug | % of all drug | Number of drug | % of all drug |
| | 21 | 100.0% | 23 | 100.0% | 23 | 100.0% |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| | 18 | 85.7% | 22 | 95.7% | 22 | 95.7% |
| | 3 | 14.3% | 1 | 4.3% | 1 | 4.3% |
| Number of payments | | | Number of payments | | Number of payments | |
| | 108 | | 125 | | 173 | |
| | 13 | | 13 | | 12 | |
| Number of drug | | % of all drug | Number of drug | % of all drug | Number of drug | % of all drug |
| | 2 | 100.0% | 1 | 100.0% | 1 | 100.0% |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| | 2 | 100.0% | 1 | 100.0% | 1 | 100.0% |
| | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| Number of payments | | | Number of payments | | Number of payments | |
| | 108 | | 125 | | 173 | |
| | 0 | | 0 | | 0 | |
| Number of drug | | % of all drug | Number of drug | % of all drug | Number of drug | % of all drug |
| | 72 | 100.0% | 74 | 100.0% | 69 | 100.0% |
| | 4 | 5.6% | 7 | 9.5% | 4 | 5.8% |

| | | | | | | |
|----|-------------------|---------------|-------------------|----------------|-------------------|--------|
| 1 | | | | | | |
| 2 | 5 | 6.9% | 9 | 12.2% | 5 | 7.2% |
| 3 | 12 | 16.7% | 17 | 23.0% | 12 | 17.4% |
| 4 | 34 | 47.2% | 28 | 37.8% | 29 | 42.0% |
| 5 | | | | | | |
| 6 | | | | | | |
| 7 | Number of drug | % of all drug | 0 | Number of drug | % of all drug | 0 |
| 8 | 55 | 100.0% | 57 | 100.0% | 50 | 100.0% |
| 9 | 1 | 1.8% | 5 | 8.8% | 3 | 6.0% |
| 10 | 2 | 3.6% | 7 | 12.3% | 4 | 8.0% |
| 11 | 9 | 16.4% | 15 | 26.3% | 11 | 22.0% |
| 12 | 20 | 36.4% | 13 | 22.8% | 11 | 22.0% |
| 13 | | | | | | |
| 14 | | | | | | |
| 15 | Number of drug | % of all drug | 0 | Number of drug | % of all drug | 0 |
| 16 | 21 | 100.0% | 23 | 100.0% | 23 | 100.0% |
| 17 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 18 | 1 | 4.8% | 0 | 0.0% | 0 | 0.0% |
| 19 | 3 | 14.3% | 4 | 17.4% | 2 | 8.7% |
| 20 | 2 | 9.5% | 1 | 4.3% | 1 | 4.3% |
| 21 | | | | | | |
| 22 | | | | | | |
| 23 | | | | | | |
| 24 | Number of drug | % of all drug | 0 | Number of drug | % of all drug | 0 |
| 25 | 2 | 100.0% | 1 | 100.0% | 100.0% | 100.0% |
| 26 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 27 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 28 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 29 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 30 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 31 | | | | | | |
| 32 | | | | | | |
| 33 | | | | | | |
| 34 | | | | | | |
| 35 | Number of drug | % of all drug | 0 | Number of drug | % of all drug | 0 |
| 36 | 59 | 100.0% | 60 | 100.0% | 55 | 100.0% |
| 37 | 0 | 0.0% | 1 | 1.7% | 0 | 0.0% |
| 38 | 39 | 66.1% | 41 | 68.3% | 38 | 69.1% |
| 39 | 20 | 33.9% | 18 | 30.0% | 17 | 30.9% |
| 40 | | | | | | |
| 41 | | | | | | |
| 42 | | | | | | |
| 43 | Value of payments | | Value of payments | | Value of payments | |
| 44 | 902,858.00 | | 1,637,974.69 | | 5,986,743.37 | |
| 45 | 2,123,196.45 | | 729,868.42 | | 5,541,099.82 | |
| 46 | | | | | | |
| 47 | | | | | | |
| 48 | Number of drug | % of all drug | 0 | Number of drug | % of all drug | 0 |
| 49 | 28 | 100.0% | 30 | 100.0% | 28 | 100.0% |
| 50 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 51 | 21 | 75.0% | 25 | 83.3% | 23 | 82.1% |
| 52 | 7 | 25.0% | 5 | 16.7% | 5 | 17.9% |
| 53 | | | | | | |
| 54 | | | | | | |
| 55 | Value of payments | | Value of payments | | Value of payments | |
| 56 | 902,858.0 | | 1,637,974.7 | | 5,986,743.4 | |
| 57 | 2,123,196.4 | | 729,868.4 | | 5,541,099.8 | |
| 58 | | | | | | |
| 59 | | | | | | |
| 60 | Number of drug | % of all drug | 0 | Number of drug | % of all drug | 0 |

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|---|--------|---|--------|---|--------|
| 3 | 100.0% | 2 | 100.0% | 2 | 100.0% |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 2 | 66.7% | 2 | 100.0% | 1 | 50.0% |
| 1 | 33.3% | 0 | 0.0% | 1 | 50.0% |

| | | |
|-------------------|-------------------|-------------------|
| Value of payments | Value of payments | Value of payments |
| 902,858.0 | 1,637,974.7 | 5,986,743.4 |
| 2,123,196.4 | - | 5,541,099.8 |

| | | | | | | | |
|----------------|---------------|----|----------------|---------------|--------|----------------|---------------|
| Number of drug | % of all drug | 0 | Number of drug | % of all drug | 0 | Number of drug | % of all drug |
| 59 | 100.0% | 60 | 100.0% | 55 | 100.0% | | |
| 1 | 1.7% | 5 | 8.3% | 0 | 0.0% | | |
| 1 | 1.7% | 8 | 13.3% | 4 | 7.3% | | |
| 8 | 13.6% | 17 | 28.3% | 14 | 25.5% | | |
| 31 | 52.5% | 24 | 40.0% | 22 | 40.0% | | |

| | | | | | | | |
|----------------|---------------|----|----------------|---------------|--------|----------------|---------------|
| Number of drug | % of all drug | 0 | Number of drug | % of all drug | 0 | Number of drug | % of all drug |
| 28 | 100.0% | 30 | 100.0% | 28 | 100.0% | | |
| 1 | 3.6% | 2 | 6.7% | 0 | 0.0% | | |
| 1 | 3.6% | 2 | 6.7% | 3 | 10.7% | | |
| 5 | 17.9% | 8 | 26.7% | 10 | 35.7% | | |
| 8 | 28.6% | 6 | 20.0% | 4 | 14.3% | | |

| | | | | | | | |
|----------------|---------------|---|----------------|---------------|--------|----------------|---------------|
| Number of drug | % of all drug | 0 | Number of drug | % of all drug | 0 | Number of drug | % of all drug |
| 3 | 100.0% | 2 | 100.0% | 2 | 100.0% | | |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | | |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | | |
| 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | | |
| 1 | 33.3% | 0 | 0.0% | 0 | 0.0% | | |

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companies at a given threshold

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companies at a given threshold

companies at a given threshold

companies

For peer review only

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companies at a given threshold

companies at a given threshold

companies at a given threshold

For peer review only

Web Supplement 5. Recipients - Absolute and relative differences in the number and value of payments (a)**NUMBER OF PAYMENTS**

Number of payments - industry data

Number of payments - patient organisation data

Number of patient organisations with at least 1 payment - industry data

Number of patient organisations with at least 1 payment - patient organisation data

NUMBER OF PAYMENTS - THRESHOLDS

Threshold 0: Number of patient organisations with at least 1 one payment in at least one dataset

Threshold 1: Number of patient organisations with more than 1 one payment in at least one dataset

Threshold 2: Number of patient organisations with more than 10 payments in at least one dataset

Threshold 3: Number of patient organisations with more than 100 payments in at least one dataset

NUMBER OF PAYMENTS - ABSOLUTE DIFFERENCES**Number of payments - threshold 0**

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

Number of payments - threshold 1

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

Number of payments - threshold 2

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

Number of payments - threshold 3

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i
 Highest absolute difference between patient organisation and industry data - number of payments higher in j

NUMBER OF PAYMENTS - RELATIVE DIFFERENCES

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 1

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 2

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 3

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES

Value of payments - industry data (2016 £)
 Value of payments - patient organisation data (2016 £)
 Number of payments with value >£0 - industry data
 Number of payments with value >£0 - patient organisation data
 Number of patient organisations with at least one payment with the value >£0 - industry data
 Number of patient organisations with at least one payment with the value >£0 - patient organisation data

VALUE OF PAYMENTS - THRESHOLDS

Threshold 1: Number of patient organisations with at least one payment with value >0 in at least one dataset
 Threshold 2: Number of patient organisations with payments with the value of more than £10,000 in at least
 Threshold 3: Number of patient organisations with payments with the value of more than £100,000 in at least

VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES

Number of payments - threshold 1

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Number of patient organisations with exact match in both datasets
 Number of patient organisations with higher payment value in industry data
 Number of patient organisations with higher payment value in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i
 Highest absolute difference between patient organisation and industry data - number of payments higher in i

Number of payments - threshold 2

Number of patient organisations with exact match in both datasets
 Number of patient organisations with higher payment value in industry data
 Number of patient organisations with higher payment value in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i
 Highest absolute difference between patient organisation and industry data - number of payments higher in i

Number of payments - threshold 3

Number of patient organisations with exact match in both datasets
 Number of patient organisations with higher payment value in industry data
 Number of patient organisations with higher payment value in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i
 Highest absolute difference between patient organisation and industry data - number of payments higher in i

VALUE OF PAYMENTS - RELATIVE DIFFERENCES

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 1

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 2

Relative difference <10%
 Relative difference <20%
 Relative difference <50%
 Relative difference = 100%

Number of payments - threshold 3

Relative difference <10%
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For peer review only

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| Total | | | | | | |
| | 4316 | | 1 | 1 | 1 | 12 |
| | 1661 | | 0 | 0 | 0 | 0 |
| | 425 | | 1 | 1 | 1 | 1 |
| | 200 | | 0 | 0 | 0 | 0 |
| Number of patien % of all patient organisations with at least one payment in at least one | | | | | | |
| | 425 | 100.0% | 1 | 1 | 1 | 1 |
| | 299 | 70.4% | | | | 1 |
| | 115 | 27.1% | | | | 1 |
| | 3 | 0.7% | | | | |
| Number of patien % of all patient organisations at a given threshold | | | | | | |
| | 33 | 7.8% | | | | |
| | 335 | 78.8% | 1 | 1 | 1 | 1 |
| | 57 | 13.4% | | | | |
| Number of payments | | | | | | |
| | 199 | | 1 | 1 | 1 | 12 |
| | 33 | | | | | |
| Number of patien % of all patient organisations at a given threshold | | | | | | |
| | 13 | 4.3% | | | | |
| | 229 | 76.6% | | | | 1 |
| | 57 | 19.1% | | | | |
| Number of payments | | | | | | |
| | 199 | | | | | 12 |
| | 33 | | | | | |
| Number of patien % of all patient organisations at a given threshold | | | | | | |
| | 2 | 1.7% | | | | |
| | 95 | 82.6% | | | | 1 |
| | 18 | 15.7% | | | | |
| Number of payments | | | | | | |
| | 199 | | | | | 12 |
| | 33 | | | | | |
| Number of patien % of all patient organisations at a given threshold | | | | | | |
| | 0 | 0.0% | | | | |
| | 3 | 100.0% | | | | |

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| 2 | 0 | 0.0% | | | | |
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| 4 | Number of payments | | | | | |
| 5 | 199 | | | | | |
| 6 | 0 | | | | | |
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| 10 | Number of patien % of all patient organisations with at least one payment in at least one | | | | | |
| 11 | 35 | 8.2% | | | | |
| 12 | 42 | 9.9% | | | | |
| 13 | 81 | 19.1% | | | | |
| 14 | 225 | 52.9% | 100.0% | 100.0% | 100.0% | 100.0% |
| 15 | | | | | | |
| 16 | | | | | | |
| 17 | Number of patien % of all patient organisations at a given threshold | | | | | |
| 18 | 15 | 5.0% | | | | |
| 19 | 22 | 7.4% | | | | |
| 20 | 61 | 20.4% | | | | |
| 21 | 119 | 39.8% | | | | 100.0% |
| 22 | | | | | | |
| 23 | Number of patien % of all patient organisations at a given threshold | | | | | |
| 24 | 4 | 3.5% | | | | |
| 25 | 7 | 6.1% | | | | |
| 26 | 31 | 27.0% | | | | |
| 27 | 33 | 28.7% | | | | 100.0% |
| 28 | | | | | | |
| 29 | Number of patien % of all patient organisations at a given threshold | | | | | |
| 30 | 0 | 0.0% | | | | |
| 31 | 0 | 0.0% | | | | |
| 32 | 0 | 0.0% | | | | |
| 33 | 1 | 33.3% | | | | |
| 34 | | | | | | |
| 35 | £54,071,454.2 | | 1029 | 5070 | 101 | 47076 |
| 36 | £33,037,955.8 | | 0 | 0 | 0 | 0 |
| 37 | 4235 | | 1 | 1 | 1 | 12 |
| 38 | 772 | | 0 | 0 | 0 | 0 |
| 39 | 416 | | 1 | 1 | 1 | 1 |
| 40 | 121 | | 0 | 0 | 0 | 0 |
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| 53 | 416 | | 1 | 1 | 1 | 1 |
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| 60 | Number of patien % of all patient organisations at a given threshold | | | | | |

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| | 8 | 1.9% | | | | |
| | 356 | 85.6% | 1 | 1 | 1 | 1 |
| | 52 | 12.5% | | | | |
| Vallue of payments | | | 0 | 0 | 0 | 0 |
| | 6,718,576.6 | | 1029 | 5070 | 101 | 47076 |
| | 6,493,237.1 | | | | | |
| Number of patien % of all patient organisations at a given threshold | | | | | | |
| | 0 | 0.0% | | | | |
| | 80 | 76.9% | | | | |
| | 24 | 23.1% | | | | |
| Vallue of payments | | | | | | |
| | 6,718,576.6 | | | | | |
| | 6,493,237.1 | | | | | |
| Number of patien % of all patient organisations at a given threshold | | | | | | |
| | 0 | 0.0% | | | | |
| | 6 | 46.2% | | | | |
| | 7 | 53.8% | | | | |
| Vallue of payments | | | | | | |
| | 6,718,576.6 | | | | | |
| | 6,493,237.1 | | | | | |
| Number of patien % of all patient organisations with at least one payment with value >£0 | | | | | | |
| | 21 | 5.0% | | | | |
| | 34 | 8.2% | | | | |
| | 73 | 17.5% | | | | |
| | 295 | 70.9% | 100.0% | 100.0% | 100.0% | 100.0% |
| | 21 | 5.0% | | | | |
| | 34 | 8.2% | | | | |
| | 73 | 17.5% | | | | |
| | 295 | 70.9% | 100.0% | 100.0% | 100.0% | 100.0% |
| | 4 | 3.8% | | | | |
| | 8 | 7.7% | | | | |
| | 23 | 22.1% | | | | |
| | 54 | 51.9% | | | | |
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For peer review only

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Anthony Nol: Anticoagulation Anxiety UK Aplastic Anaemia Arrhythmia A Arthritis and Arthritis Care

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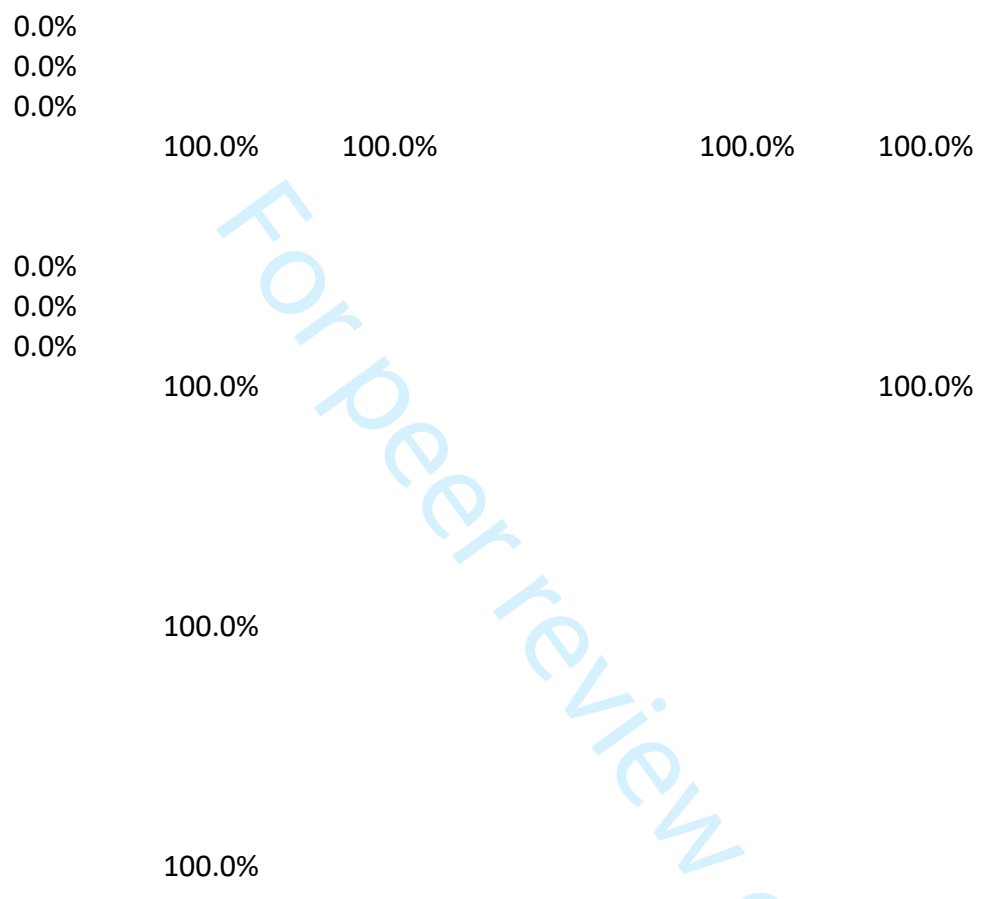
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For peer review only

Beat Parkinson's Beating Bowel Cancer Behcets Syndrome Bipolar Scotland Bipolar UK Birdshot Uveitis Bladder and Bowel Cancer

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For peer review only

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For peer review only

Bowel Cancer Brain Charity Brain Tumor Brain Tumou Breakthrough Breast Cance Breast Cance

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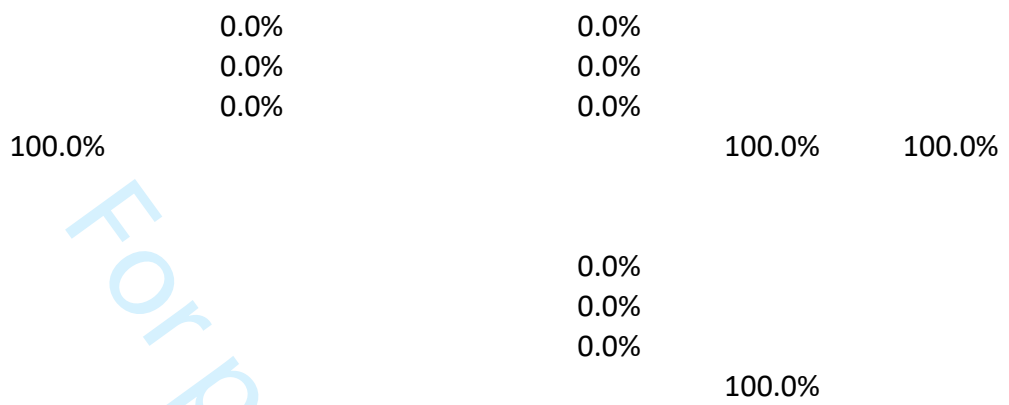
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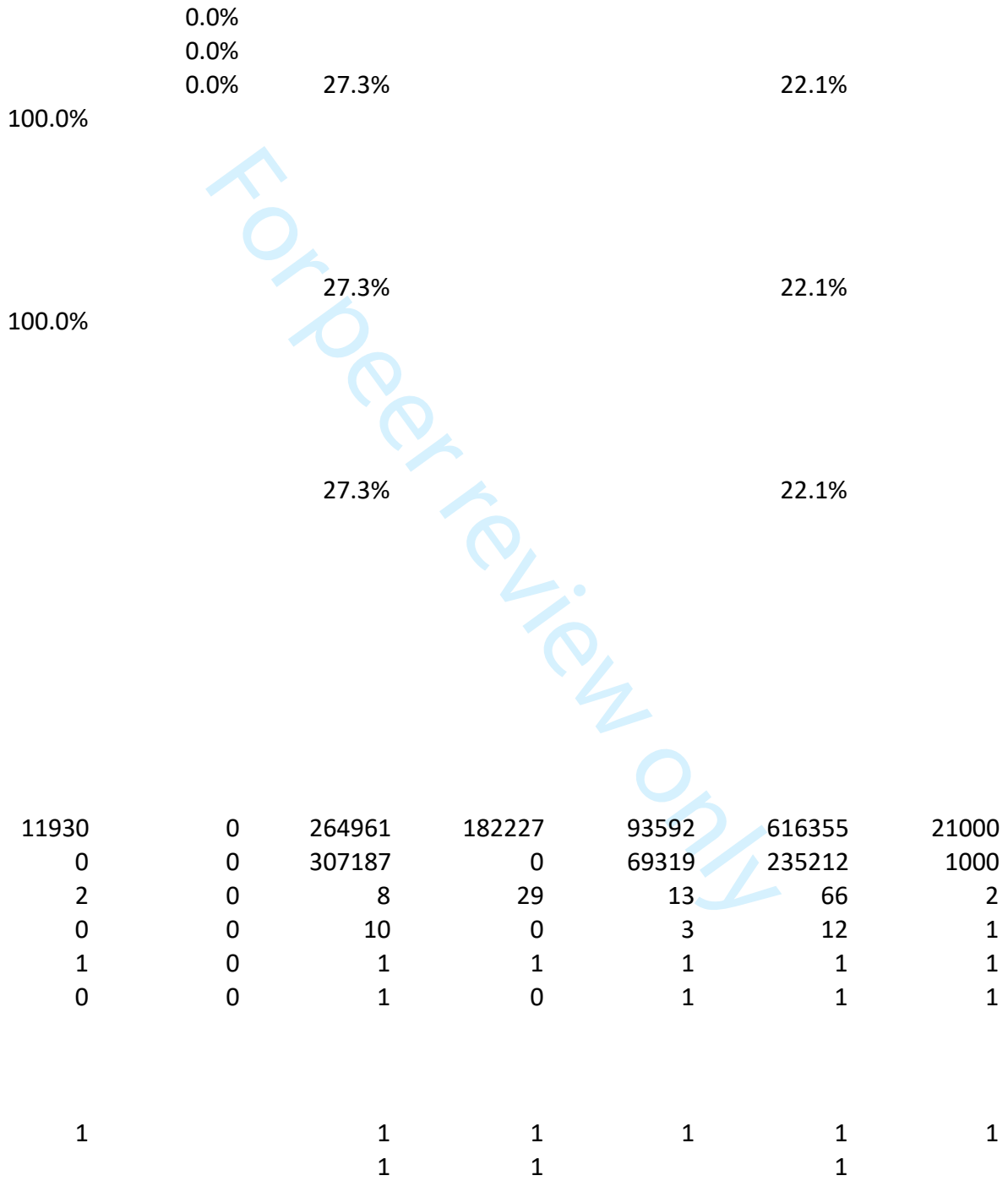
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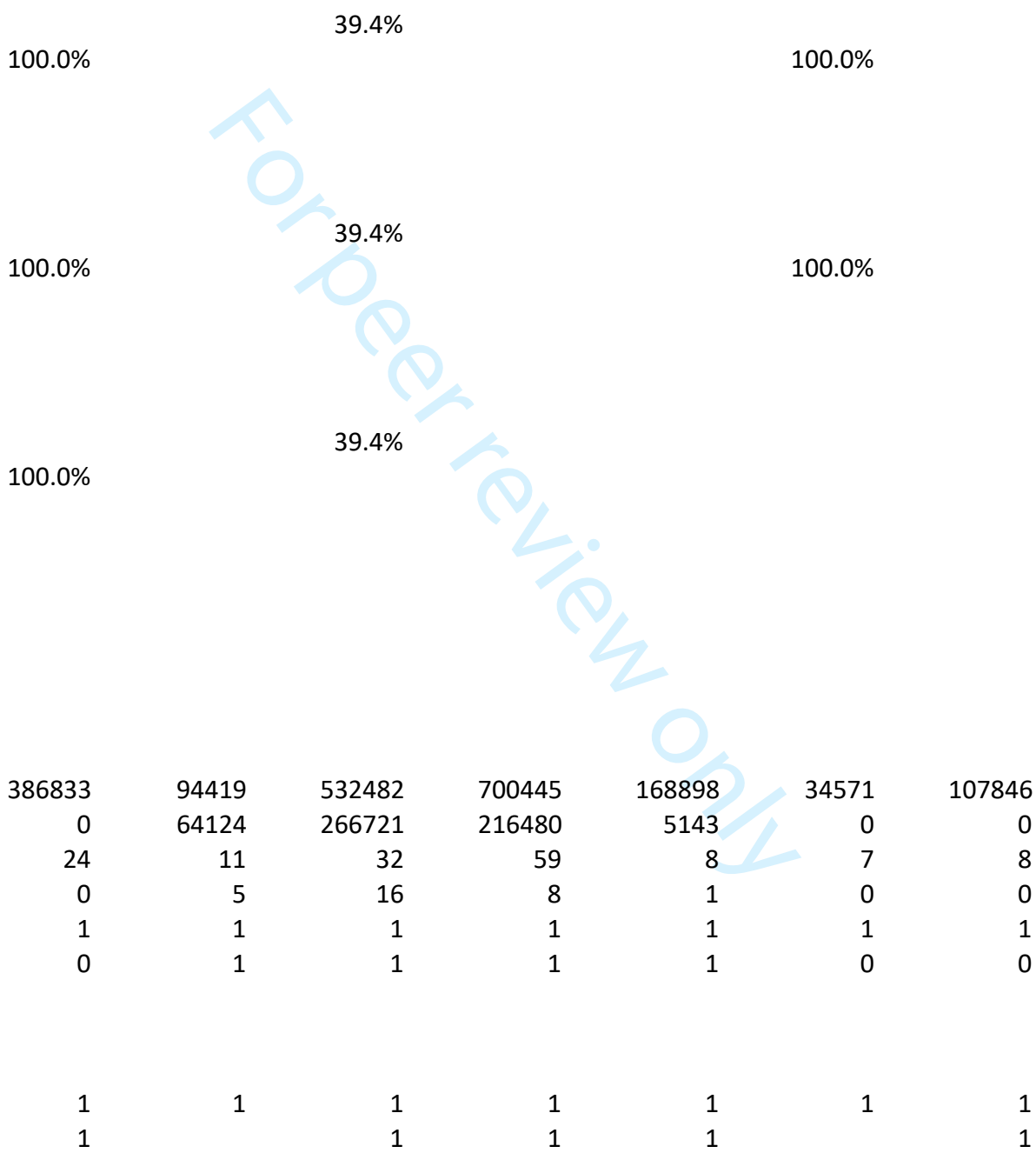
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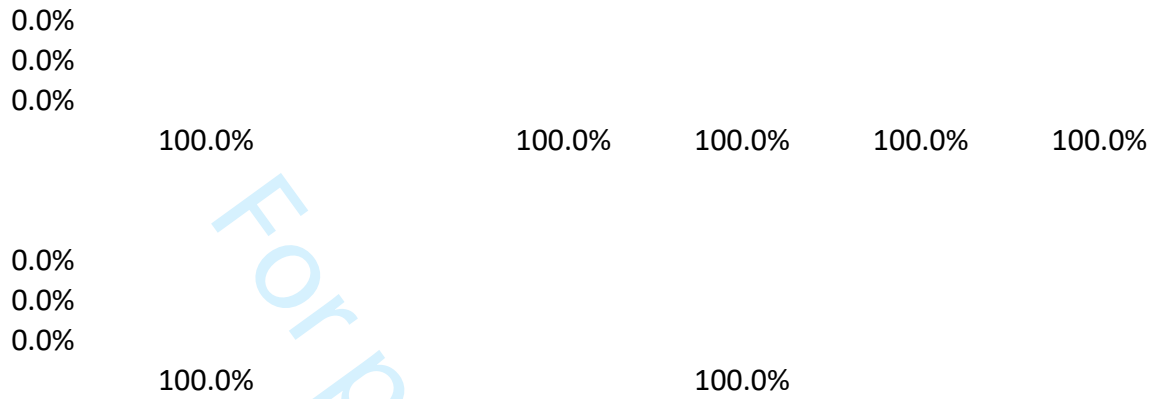
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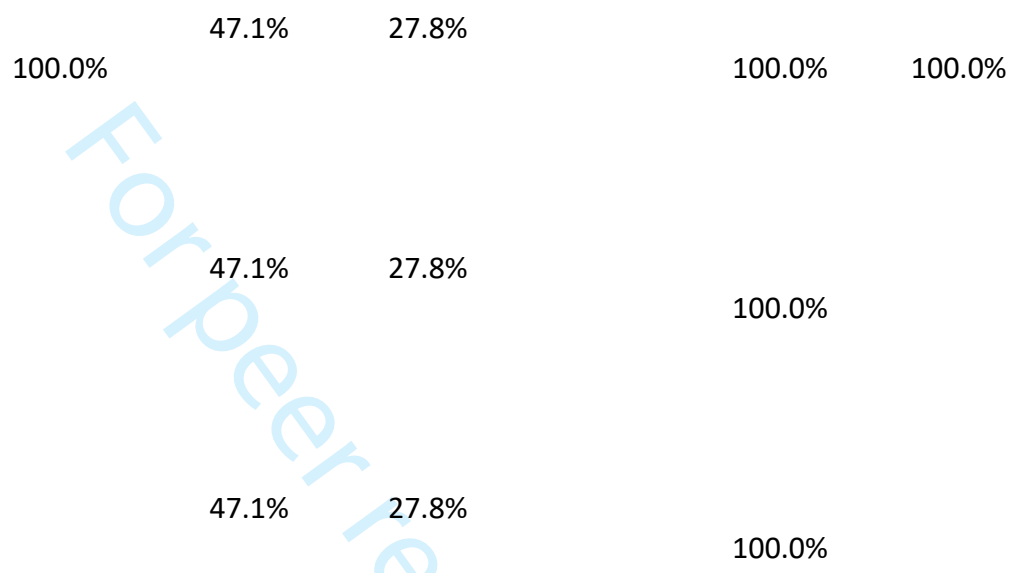
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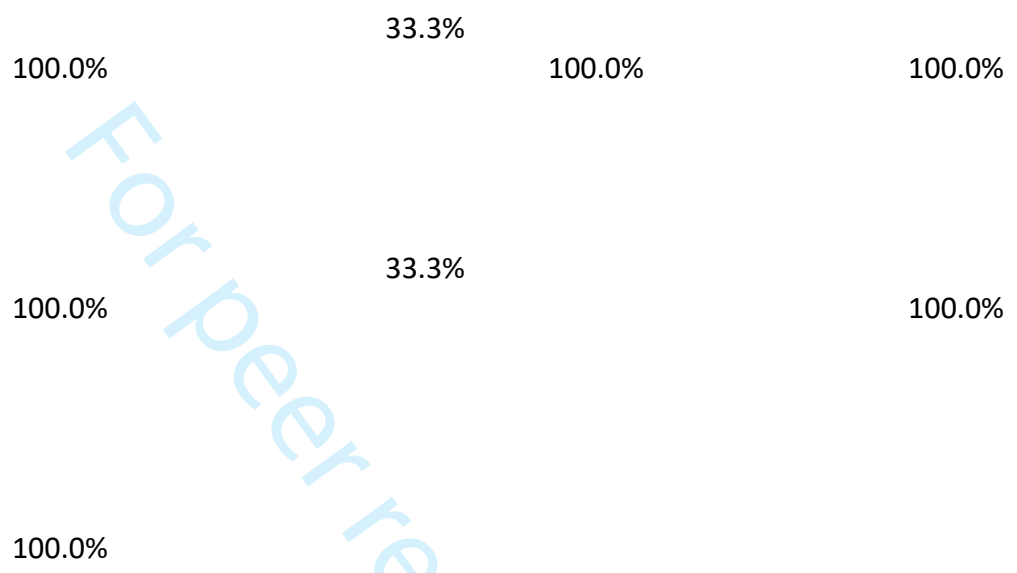
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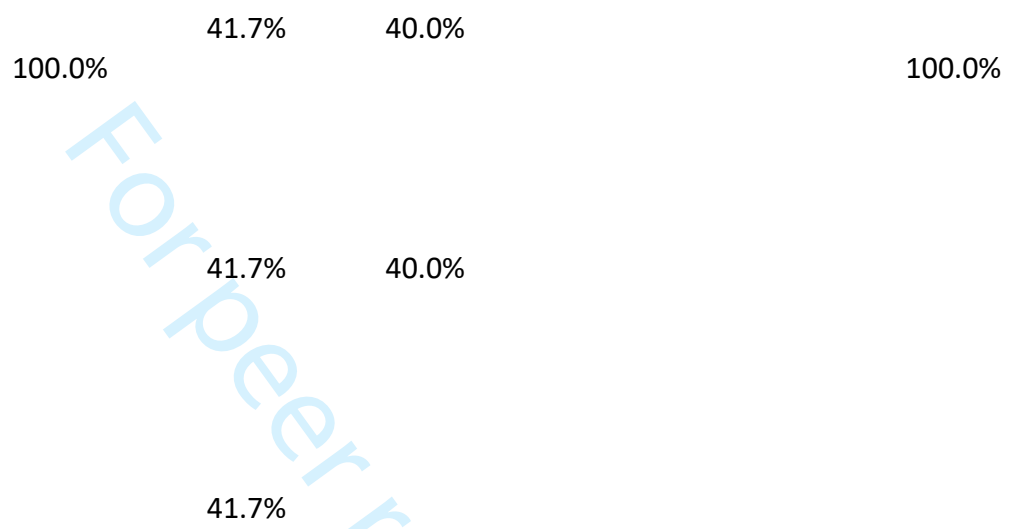
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Web Supplement 6. Recipients - Absolute and relative differences in the number and value of payments (in**NUMBER OF PAYMENTS - ABSOLUTE DIFFERENCES****Threshold 0: At least 1 one payment in at least one dataset**

Total

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

Threshold 1: More than 1 one payment in at least one dataset

Total

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

Threshold 2: More than 10 payments in at least one dataset

Total

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

Threshold 3: More than 100 payments in at least one dataset

Total

Number of patient organisations with exact match in both datasets

Number of patient organisations with more payments in industry data

Number of patient organisations with more payments in patient organisation data

Highest absolute difference between patient organisation and industry data - number of payments higher in i

Highest absolute difference between patient organisation and industry data - number of payments higher in j

NUMBER OF PAYMENTS - RELATIVE DIFFERENCES**Threshold 0: At least 1 one payment in at least one dataset**

Total

Relative difference <10%

1
2 Relative difference <20%
3 Relative difference <50%
4 Relative difference = 100%

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7 **Threshold 1: More than 1 one payment in at least one dataset**

8 Total
9 Relative difference <10%
10 Relative difference <20%
11 Relative difference <50%
12 Relative difference = 100%

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15 **Threshold 2: More than 10 payments in at least one dataset**

16 Total
17 Relative difference <10%
18 Relative difference <20%
19 Relative difference <50%
20 Relative difference = 100%

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23 **Threshold 3: More than 100 payments in at least one dataset**

24 Total
25 Relative difference <10%
26 Relative difference <20%
27 Relative difference <50%
28 Relative difference = 100%

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33 **VALUE OF PAYMENTS - ABSOLUTE DIFFERENCES**

34
35 **Threshold 1: At least one payment with value >£0 in at least one dataset**

36 Total
37 Number of patient organisations with exact match in both datasets
38 Number of patient organisations with higher payment value in industry data
39 Number of patient organisations with higher payment value in patient organisation data

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44 Highest absolute difference between patient organisation and industry data - number of payments higher in i
45 Highest absolute difference between patient organisation and industry data - number of payments higher in j

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48 **Threshold 2: Payments with the value of more than £10,000 in at least one dataset**

49 Total
50 Number of patient organisations with exact match in both datasets
51 Number of patient organisations with higher payment value in industry data
52 Number of patient organisations with higher payment value in patient organisation data

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57 Highest absolute difference between patient organisation and industry data - number of payments higher in i
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60 **Threshold 3: Payments with the value of more than £100,000 in at least one dataset**

1
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3 Number of patient organisations with exact match in both datasets

4 Number of patient organisations with higher payment value in industry data

5 Number of patient organisations with higher payment value in patient organisation data

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9 Highest absolute difference between patient organisation and industry data - number of payments higher in i

10 Highest absolute difference between patient organisation and industry data - number of payments higher in j

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13 **VALUE OF PAYMENTS - RELATIVE DIFFERENCES**

14
15 **Threshold 1: At least one payment with value >£0 in at least one dataset**

16 Total

17 Relative difference <10%

18 Relative difference <20%

19 Relative difference <50%

20 Relative difference = 100%

21
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24 **Threshold 2: Payments with the value of more than £10,000 in at least one dataset**

25 Total

26 Relative difference <10%

27 Relative difference <20%

28 Relative difference <50%

29 Relative difference = 100%

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33 **Threshold 3: Payments with the value of more than £100,000 in at least one dataset**

34 Total

35 Relative difference <10%

36 Relative difference <20%

37 Relative difference <50%

38 Relative difference = 100%

| All years | | 2012 | | 2013 | |
|--------------------|-------------------|--------------------|-------------------|--------------------|-------------------|
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |
| 425 | 100.0% | 219 | 100.0% | 225 | 100.0% |
| 33 | 7.8% | 17 | 7.8% | 18 | 8.0% |
| 335 | 78.8% | 160 | 73.1% | 157 | 69.8% |
| 57 | 13.4% | 42 | 19.2% | 50 | 22.2% |
| Number of payments | | Number of payments | | Number of payments | |
| 199 | | 36 | | 35 | |
| 33 | | 9 | | 17 | |
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |
| 299 | 100.0% | 140 | 100.0% | 137 | 100.0% |
| 13 | 4.3% | 6 | 4.3% | 9 | 6.6% |
| 229 | 76.6% | 105 | 75.0% | 95 | 69.3% |
| 57 | 19.1% | 29 | 20.7% | 33 | 24.1% |
| Number of payments | | Number of payments | | Number of payments | |
| 199 | | 36 | | 35 | |
| 33 | | 9 | | 17 | |
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |
| 115 | 100.0% | 20 | 100.0% | 13 | 100.0% |
| 2 | 1.7% | 1 | 5.0% | 0 | 0.0% |
| 95 | 82.6% | 16 | 80.0% | 9 | 69.2% |
| 18 | 15.7% | 3 | 15.0% | 4 | 30.8% |
| Number of payments | | Number of payments | | Number of payments | |
| 199 | | 36 | | 35 | |
| 33 | | 9 | | 17 | |
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |
| 3 | 100.0% | 0 | N/A | 0 | N/A |
| 0 | 0.0% | N/A | N/A | N/A | N/A |
| 3 | 100.0% | N/A | N/A | N/A | N/A |
| 0 | 0.0% | N/A | N/A | N/A | N/A |
| Number of payments | | Number of payments | | Number of payments | |
| 199 | | 0 | | 0 | |
| 0 | | 0 | | 0 | |
| Number of patients | % of all patients | Number of patients | % of all patients | Number of patients | % of all patients |
| 425 | 100.0% | 219 | 100.0% | 225 | 100.0% |
| 35 | 8.2% | 17 | 7.8% | 18 | 8.0% |

| | | | | | | |
|----|-------------------|------------------|-------------------|------------------|-------------------|------------------|
| 1 | | | | | | |
| 2 | 42 | 9.9% | 18 | 8.2% | 19 | 8.4% |
| 3 | 81 | 19.1% | 30 | 13.7% | 34 | 15.1% |
| 4 | 225 | 52.9% | 138 | 63.0% | 150 | 66.7% |
| 5 | | | | | | |
| 6 | | | | | | |
| 7 | Number of pa | % of all patient | Number of pa | % of all patient | Number of pa | % of all patient |
| 8 | 299 | 100.0% | 140 | 100.0% | 137 | 100.0% |
| 9 | 15 | 5.0% | 6 | 4.3% | 9 | 6.6% |
| 10 | 22 | 7.4% | 7 | 5.0% | 10 | 7.3% |
| 11 | 61 | 20.4% | 19 | 13.6% | 25 | 18.2% |
| 12 | 119 | 39.8% | 70 | 50.0% | 71 | 51.8% |
| 13 | | | | | | |
| 14 | | | | | | |
| 15 | | | | | | |
| 16 | Number of pa | % of all patient | Number of pa | % of all patient | Number of pa | % of all patient |
| 17 | 115 | 100.0% | 20 | 100.0% | 13 | 100.0% |
| 18 | 4 | 3.5% | 1 | 5.0% | 0 | 0.0% |
| 19 | 7 | 6.1% | 2 | 10.0% | 0 | 0.0% |
| 20 | 31 | 27.0% | 4 | 20.0% | 1 | 7.7% |
| 21 | 33 | 28.7% | 7 | 35.0% | 5 | 38.5% |
| 22 | | | | | | |
| 23 | | | | | | |
| 24 | Number of pa | % of all patient | Number of pa | % of all patient | Number of pa | % of all patient |
| 25 | 3 | 100.0% | 0 | N/A | 0 | N/A |
| 26 | 0 | 0.0% | N/A | N/A | N/A | N/A |
| 27 | 0 | 0.0% | N/A | N/A | N/A | N/A |
| 28 | 0 | 0.0% | N/A | N/A | N/A | N/A |
| 29 | 0 | 0.0% | N/A | N/A | N/A | N/A |
| 30 | 1 | 33.3% | N/A | N/A | N/A | N/A |
| 31 | | | | | | |
| 32 | | | | | | |
| 33 | | | | | | |
| 34 | | | | | | |
| 35 | | | | | | |
| 36 | Number of pa | % of all patient | Number of pa | % of all patient | Number of pa | % of all patient |
| 37 | 416 | 100.0% | 206 | 100.0% | 204 | 100.0% |
| 38 | 8 | 1.9% | 4 | 1.9% | 4 | 2.0% |
| 39 | 356 | 85.6% | 168 | 81.6% | 164 | 80.4% |
| 40 | 52 | 12.5% | 34 | 16.5% | 36 | 17.6% |
| 41 | | | | | | |
| 42 | | | | | | |
| 43 | Value of payments | | Value of payments | | Value of payments | |
| 44 | 6,718,576.6 | | 660,846.1 | | 369,657.9 | |
| 45 | 6,493,237.1 | | 283,684.7 | | 829,991.7 | |
| 46 | | | | | | |
| 47 | | | | | | |
| 48 | Number of pa | % of all patient | Number of pa | % of all patient | Number of pa | % of all patient |
| 49 | 104 | 100.0% | 29 | 100.0% | 20 | 100.0% |
| 50 | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| 51 | 80 | 76.9% | 19 | 65.5% | 12 | 60.0% |
| 52 | 24 | 23.1% | 10 | 34.5% | 8 | 40.0% |
| 53 | | | | | | |
| 54 | | | | | | |
| 55 | | | | | | |
| 56 | Value of payments | | Value of payments | | Value of payments | |
| 57 | 6,718,576.6 | | 660,846.1 | | 369,657.9 | |
| 58 | 6,493,237.1 | | 283,684.7 | | 829,991.7 | |
| 59 | | | | | | |
| 60 | Number of pa | % of all patient | Number of pa | % of all patient | Number of pa | % of all patient |

| | | | | | | | |
|--------------------|--------|--------------------|--------|--------------------|--------|--------------------|-----|
| 13 | 100.0% | | 0 | N/A | | 0 | N/A |
| 0 | 0.0% | N/A | | N/A | | | N/A |
| 6 | 46.2% | N/A | | N/A | | | N/A |
| 7 | 53.8% | N/A | | N/A | | | N/A |
| Value of payments | | Value of payments | | Value of payments | | | |
| 6,718,576.6 | | - | | - | | | |
| 6,493,237.1 | | - | | - | | | |
| Number of patients | | Number of patients | | Number of patients | | Number of patients | |
| % of all patients | | % of all patients | | % of all patients | | % of all patients | |
| 416 | 100.0% | 206 | 100.0% | 204 | 100.0% | | |
| 21 | 5.0% | 6 | 2.9% | 8 | 3.9% | | |
| 34 | 8.2% | 11 | 5.3% | 13 | 6.4% | | |
| 73 | 17.5% | 20 | 9.7% | 21 | 10.3% | | |
| 295 | 70.9% | 158 | 76.7% | 164 | 80.4% | | |
| Number of patients | | Number of patients | | Number of patients | | Number of patients | |
| % of all patients | | % of all patients | | % of all patients | | % of all patients | |
| 104 | 100.0% | 29 | 100.0% | 20 | 100.0% | | |
| 4 | 3.8% | 0 | 0.0% | 0 | 0.0% | | |
| 8 | 7.7% | 2 | 6.9% | 0 | 0.0% | | |
| 23 | 22.1% | 4 | 13.8% | 2 | 10.0% | | |
| 54 | 51.9% | 17 | 58.6% | 11 | 55.0% | | |
| Number of patients | | Number of patients | | Number of patients | | Number of patients | |
| % of all patients | | % of all patients | | % of all patients | | % of all patients | |
| 13 | 100.0% | 0 | N/A | 0 | N/A | | |
| 0 | 0.0% | N/A | N/A | N/A | N/A | | |
| 0 | 0.0% | N/A | N/A | N/A | N/A | | |
| 3 | 23.1% | N/A | N/A | N/A | N/A | | |
| 4 | 30.8% | N/A | N/A | N/A | N/A | | |

| | 2014 | | 2015 | | 2016 |
|--------------------|------|--------|------|--------|------|
| Number of patients | 247 | 100.0% | 267 | 100.0% | 260 |
| Number of patients | 29 | 11.7% | 31 | 11.6% | 21 |
| Number of patients | 173 | 70.0% | 186 | 69.7% | 208 |
| Number of patients | 45 | 18.2% | 50 | 18.7% | 31 |
| Number of payments | 36 | | 44 | | 55 |
| Number of payments | 15 | | 10 | | 11 |
| Number of patients | 146 | 100.0% | 149 | 100.0% | 166 |
| Number of patients | 6 | 4.1% | 8 | 5.4% | 7 |
| Number of patients | 110 | 75.3% | 107 | 71.8% | 138 |
| Number of patients | 30 | 20.5% | 34 | 22.8% | 21 |
| Number of payments | 36 | | 44 | | 55 |
| Number of payments | 15 | | 10 | | 11 |
| Number of patients | 15 | 100.0% | 22 | 100.0% | 29 |
| Number of patients | 0 | 0.0% | 0 | 0.0% | 0 |
| Number of patients | 11 | 73.3% | 19 | 86.4% | 26 |
| Number of patients | 4 | 26.7% | 3 | 13.6% | 3 |
| Number of payments | 36 | | 44 | | 55 |
| Number of payments | 15 | | 10 | | 11 |
| Number of patients | 0 | N/A | 0 | N/A | 0 |
| Number of patients | N/A | N/A | N/A | N/A | N/A |
| Number of patients | N/A | N/A | N/A | N/A | N/A |
| Number of patients | N/A | N/A | N/A | N/A | N/A |
| Number of payments | 0 | | 0 | | 0 |
| Number of payments | 0 | | 0 | | 0 |
| Number of patients | 247 | 100.0% | 267 | 100.0% | 260 |
| Number of patients | 29 | 11.7% | 31 | 11.6% | 21 |

| | | | | | |
|---|-----|-------|-----|-------|-----|
| 1 | | | | | |
| 2 | 32 | 13.0% | 33 | 12.4% | 24 |
| 3 | 48 | 19.4% | 49 | 18.4% | 45 |
| 4 | 153 | 61.9% | 164 | 61.4% | 159 |

| | | | | | |
|----|---------------------------------|--------|---|--------|----------------|
| 7 | Number of pati % of all patient | | Number of pati % of all patient organisatic | | Number of pati |
| 8 | 146 | 100.0% | 149 | 100.0% | 166 |
| 9 | 6 | 4.1% | 8 | 5.4% | 7 |
| 10 | 9 | 6.2% | 10 | 6.7% | 10 |
| 11 | 25 | 17.1% | 26 | 17.4% | 31 |
| 12 | 75 | 51.4% | 69 | 46.3% | 79 |

| | | | | | |
|----|---------------------------------|--------|---|--------|----------------|
| 15 | Number of pati % of all patient | | Number of pati % of all patient organisatic | | Number of pati |
| 16 | 15 | 100.0% | 22 | 100.0% | 29 |
| 17 | 0 | 0.0% | 0 | 0.0% | 0 |
| 18 | 1 | 6.7% | 1 | 4.5% | 1 |
| 19 | 3 | 20.0% | 4 | 18.2% | 6 |
| 20 | 5 | 33.3% | 7 | 31.8% | 13 |

| | | | | | |
|----|---------------------------------|-----|---|-----|----------------|
| 24 | Number of pati % of all patient | | Number of pati % of all patient organisatic | | Number of pati |
| 25 | 0 | N/A | 0 | N/A | 0 |
| 26 | N/A | N/A | N/A | N/A | N/A |
| 27 | N/A | N/A | N/A | N/A | N/A |
| 28 | N/A | N/A | N/A | N/A | N/A |
| 29 | N/A | N/A | N/A | N/A | N/A |
| 30 | N/A | N/A | N/A | N/A | N/A |

| | | | | | |
|----|---------------------------------|--------|---|--------|----------------|
| 35 | Number of pati % of all patient | | Number of pati % of all patient organisatic | | Number of pati |
| 36 | 234 | 100.0% | 249 | 100.0% | 249 |
| 37 | 11 | 4.7% | 15 | 6.0% | 8 |
| 38 | 196 | 83.8% | 198 | 79.5% | 211 |
| 39 | 27 | 11.5% | 36 | 14.5% | 30 |

| | | | | | |
|----|-------------------|--|-------------------|--|----------------|
| 43 | Value of payments | | Value of payments | | Value of payme |
| 44 | 538,969.2 | | 1,473,965.2 | | 6,006,677.7 |
| 45 | 1,824,997.0 | | 815,956.8 | | 6,493,237.1 |

| | | | | | |
|----|---------------------------------|--------|---|--------|----------------|
| 48 | Number of pati % of all patient | | Number of pati % of all patient organisatic | | Number of pati |
| 49 | 31 | 100.0% | 34 | 100.0% | 36 |
| 50 | 0 | 0.0% | 0 | 0.0% | 0 |
| 51 | 24 | 77.4% | 25 | 73.5% | 25 |
| 52 | 7 | 22.6% | 9 | 26.5% | 11 |

| | | | | | |
|----|-------------------|--|-------------------|--|----------------|
| 55 | Value of payments | | Value of payments | | Value of payme |
| 56 | 538,969.2 | | 1,473,965.2 | | 6,006,677.7 |
| 57 | 1,824,997.0 | | 815,956.8 | | 6,493,237.1 |

| | | | | | |
|----|---------------------------------|--|---|--|----------------|
| 60 | Number of pati % of all patient | | Number of pati % of all patient organisatic | | Number of pati |
|----|---------------------------------|--|---|--|----------------|

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|---|---|--------|---|--------|---|
| 1 | | | | | |
| 2 | 1 | 100.0% | 1 | 100.0% | 2 |
| 3 | 0 | 0.0% | 0 | 0.0% | 0 |
| 4 | 0 | 0.0% | 1 | 100.0% | 1 |
| 5 | 1 | 100.0% | 0 | 0.0% | 1 |

| | | | | | |
|----|-------------------|-------------------|-------------------|-------------------|-------------------|
| 8 | Value of payments | Value of payments | Value of payments | Value of payments | Value of payments |
| 9 | - | 1,473,965.24 | - | 6,006,677.66 | - |
| 10 | 1,824,996.99 | - | - | 6,493,237.05 | - |

| | | | | | |
|----|--------------------|-------------------|--------------------|-------------------|--------------------|
| 15 | Number of patients | % of all patients | Number of patients | % of all patients | Number of patients |
| 16 | 234 | 100.0% | 249 | 100.0% | 249 |
| 17 | 16 | 6.8% | 20 | 8.0% | 18 |
| 18 | 19 | 8.1% | 25 | 10.0% | 26 |
| 19 | 28 | 12.0% | 39 | 15.7% | 36 |
| 20 | 185 | 79.1% | 189 | 75.9% | 197 |

| | | | | | |
|----|--------------------|-------------------|--------------------|-------------------|--------------------|
| 24 | Number of patients | % of all patients | Number of patients | % of all patients | Number of patients |
| 25 | 31 | 100.0% | 34 | 100.0% | 36 |
| 26 | 1 | 3.2% | 0 | 0.0% | 2 |
| 27 | 2 | 6.5% | 0 | 0.0% | 4 |
| 28 | 5 | 16.1% | 5 | 14.7% | 8 |
| 29 | 20 | 64.5% | 21 | 61.8% | 20 |

| | | | | | |
|----|--------------------|-------------------|--------------------|-------------------|--------------------|
| 33 | Number of patients | % of all patients | Number of patients | % of all patients | Number of patients |
| 34 | 1 | 100.0% | 1 | 100.0% | 2 |
| 35 | 0 | 0.0% | 0 | 0.0% | 0 |
| 36 | 0 | 0.0% | 0 | 0.0% | 0 |
| 37 | 0 | 0.0% | 0 | 0.0% | 0 |
| 38 | 0 | 0.0% | 0 | 0.0% | 0 |
| 39 | 0 | 0.0% | 1 | 100.0% | 0 |

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6 % of all patient organisationsa given threshold

7 100.0%

8 8.1%

9 80.0%

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18 % of all patient organisationsa given threshold

19 100.0%

20 4.2%

21 83.1%

22 12.7%

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30 % of all patient organisationsa given threshold

31 100.0%

32 0.0%

33 89.7%

34 10.3%

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37 nents

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42 % of all patient organisationsa given threshold

43 N/A

44 N/A

45 N/A

46 N/A

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49 nents

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58 % of all patient organisationsa given threshold

59 100.0%

60 8.1%

| | |
|----|---|
| 1 | |
| 2 | 9.2% |
| 3 | 17.3% |
| 4 | 61.2% |
| 5 | |
| 6 | |
| 7 | % of all patient organisationsa given threshold |
| 8 | 100.0% |
| 9 | 4.2% |
| 10 | 6.0% |
| 11 | 18.7% |
| 12 | 47.6% |
| 13 | |
| 14 | |
| 15 | % of all patient organisationsa given threshold |
| 16 | 100.0% |
| 17 | 0.0% |
| 18 | 3.4% |
| 19 | 20.7% |
| 20 | 44.8% |
| 21 | |
| 22 | |
| 23 | |
| 24 | % of all patient organisationsa given threshold |
| 25 | N/A |
| 26 | N/A |
| 27 | N/A |
| 28 | N/A |
| 29 | N/A |
| 30 | N/A |
| 31 | N/A |
| 32 | |
| 33 | |
| 34 | |
| 35 | % of all patient organisationsa given threshold |
| 36 | 100.0% |
| 37 | 3.2% |
| 38 | 84.7% |
| 39 | 12.0% |
| 40 | |
| 41 | |
| 42 | |
| 43 | nts |
| 44 | |
| 45 | |
| 46 | |
| 47 | |
| 48 | % of all patient organisationsa given threshold |
| 49 | 100.0% |
| 50 | 0.0% |
| 51 | 69.4% |
| 52 | 30.6% |
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| 60 | % of all patient organisationsa given threshold |

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% of all patient organisationsa given threshold

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7.2%
10.4%
14.5%
79.1%

% of all patient organisationsa given threshold

100.0%
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11.1%
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55.6%

% of all patient organisationsa given threshold

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For peer review only

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Web Supplement 7. Donors - summary of payments missing from

Year
2012
2013
2014
2015
2016

Total missing - calculated annually
Total missing - calculated for all years

For peer review only

industry data**Number of companies missing from industry data:**

31

30

27

23

0

N/A**24**

For peer review only

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Companies missing from industry dataset as a share of companies in industry

103.3%
78.9%
60.0%
45.1%
0.0%

N/A
38.1%

For peer review only

Number of payments missing from industry data: Number of payments missing from industry data:

| | |
|------------|--------------|
| 124 | 16.1% |
| 131 | 18.6% |
| 74 | 9.0% |
| 52 | 5.6% |
| 54 | 5.0% |
| 435 | 10.1% |
| 128 | 3.0% |

For peer review only

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Value of payments missing from industry data Value of payments missing from industry datas as a

| | |
|--------------------|--------------|
| 1,731,257.8 | 22.2% |
| 2,666,247.8 | 43.1% |
| 218,768.4 | 2.5% |
| 1,367,440.0 | 12.0% |
| 474,975.0 | 2.4% |
| 6,458,689.1 | 11.9% |
| 1,610,321.1 | 3.0% |

For peer review only

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3 **share of payments in industry datas**
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For peer review only

Web Supplement 8. Donors - payments missing from industry data (yearly breakdown)

| Year | Drug company name | Number of payments | Value of payments (2016 £) | |
|-----------------|-------------------------|--------------------|----------------------------|---------|
| 2012 | Alcon | 3 | 18937.5 | |
| | Alexion | 1 | 0.0 | |
| | ApoPharma | 1 | 23145.8 | |
| | Baxter | 7 | 170239.7 | |
| | Bayer | 8 | 205156.3 | |
| | BioMarin | 1 | 0.0 | |
| | Biotest | 1 | 22480.9 | |
| | Boehringer Ingelheim | 2 | 9468.8 | |
| | Dermal | 3 | 0.0 | |
| | Eisai | 1 | 0.0 | |
| | Flynn Pharma | 1 | 2104.2 | |
| | Fresenius Medical Care | 1 | 7890.6 | |
| | Genzyme | 9 | 116178.4 | |
| | Gilead | 8 | 50500.0 | |
| | GSK | 18 | 501114.7 | |
| | Ipsen | 3 | 25250.0 | |
| | Janssen | 12 | 50804.1 | |
| | LEO Pharma | 2 | 0.0 | |
| | Norgine | 1 | 0.0 | |
| | Novo Nordisk | 3 | 0.0 | |
| | Octapharma | 1 | 134882.3 | |
| | Pharma Mar | 1 | 6312.5 | |
| | RB | 1 | 83114.6 | |
| | Roche Products | 13 | 237981.3 | |
| | Sanofi Pasteur MSD | 1 | 20989.1 | |
| | Sigma Tau Rare Diseases | 1 | 0.0 | |
| | Sobi | 1 | 1052.1 | |
| | Takeda | 6 | 23145.8 | |
| | Teva | 5 | 15248.9 | |
| | UCB | 7 | 5260.4 | |
| | Veriton | 1 | 0.0 | |
| | 2013 | Alcon | 4 | 64796.3 |
| | | Alexion | 2 | 5142.6 |
| Almirall | | 2 | 0.0 | |
| Amdipharm | | 1 | 0.0 | |
| ApoPharma | | 3 | 22627.3 | |
| Bausch and Lomb | | 2 | 22627.3 | |
| Baxter | | 3 | 135138.4 | |
| Bayer | | 9 | 299046.4 | |
| Britannia | | 1 | 0.0 | |
| Dermal | | 3 | 0.0 | |
| Gedeon Richter | | 1 | 0.0 | |
| Genzyme | | 9 | 278174.8 | |
| Gilead | | 10 | 116016.3 | |
| GSK | | 16 | 406794.5 | |
| Ipsen | | 2 | 20570.3 | |

| | | | | |
|----|------|--------------------------|----|-----------|
| 1 | | | | |
| 2 | 2013 | IQVIA | 1 | 0.0 |
| 3 | | Janssen | 13 | 42110.4 |
| 4 | | LEO Pharma | 4 | 0.0 |
| 5 | | Lundbeck | 1 | 0.0 |
| 6 | | Meda | 1 | 0.0 |
| 7 | | Merck | 8 | 238799.2 |
| 8 | | Norgine | 2 | 0.0 |
| 9 | | Orphan Europe | 1 | 1028.5 |
| 10 | | PTC | 2 | 0.0 |
| 11 | | RB | 2 | 30855.4 |
| 12 | | Roche Products | 14 | 126301.4 |
| 13 | | Sigma Tau Rare Diseases | 2 | 514.3 |
| 14 | | Takeda | 9 | 4695.2 |
| 15 | | Veriton | 1 | 0.0 |
| 16 | | Vifor Pharma Group | 2 | 851009.3 |
| 17 | | Actavis | 1 | 0.0 |
| 18 | | Alcon | 1 | 0.0 |
| 19 | | Alexion | 5 | 15210.8 |
| 20 | | Alliance | 1 | 0.0 |
| 21 | | Amdipharm | 1 | 18253.0 |
| 22 | | ApoPharma | 1 | 30421.7 |
| 23 | | Baxter | 2 | 70948.4 |
| 24 | | Bayer | 4 | 27301.4 |
| 25 | | Britannia | 1 | 0.0 |
| 26 | | Dermal | 2 | 0.0 |
| 27 | | Gedeon Richter | 1 | 0.0 |
| 28 | | Genzyme | 13 | 225781.6 |
| 29 | | GSK | 12 | 2123196.4 |
| 30 | 2014 | Ipsen | 2 | 34873.4 |
| 31 | | Meda | 1 | 0.0 |
| 32 | | Mitsubishi Tanabe Pharma | 1 | 5070.3 |
| 33 | | Norgine | 2 | 16884.0 |
| 34 | | Novo Nordisk | 4 | 16144.8 |
| 35 | | Orion Pharma | 1 | 0.0 |
| 36 | | PTC | 2 | 0.0 |
| 37 | | Rosemont Pharmaceuticals | 1 | 0.0 |
| 38 | | Sigma Tau Rare Diseases | 2 | 28869.2 |
| 39 | | Stirling Anglian | 1 | 0.0 |
| 40 | | Syner-Med | 2 | 0.0 |
| 41 | | Teva | 6 | 7098.4 |
| 42 | | Veriton | 2 | 0.0 |
| 43 | | Vifor Pharma Group | 2 | 470654.9 |
| 44 | | Actavis | 2 | 24240.0 |
| 45 | | Aegerion | 1 | 0.0 |
| 46 | | ALK-Abello | 1 | 0.0 |
| 47 | | Amdipharm | 1 | 15680.3 |
| 48 | | Bausch and Lomb | 1 | 0.0 |
| 49 | | Britannia | 1 | 0.0 |
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| 1 | | | | |
| 2 | | Dermal | 3 | 0.0 |
| 3 | | Fresenius Medical Care | 1 | 5050.0 |
| 4 | | Genzyme | 9 | 257424.8 |
| 5 | | GSK | 13 | 211609.1 |
| 6 | | HRA Pharma | 1 | 0.0 |
| 7 | | | | |
| 8 | 2015 | Norgine | 3 | 16816.5 |
| 9 | | Octapharma | 2 | 64864.2 |
| 10 | | Orphan Europe | 1 | 0.0 |
| 11 | | Pharma Mar | 1 | 0.0 |
| 12 | | PTC | 1 | 0.0 |
| 13 | | RB | 1 | 30300.0 |
| 14 | | Sanofi Pasteur MSD | 1 | 0.0 |
| 15 | | Santen | 1 | 0.0 |
| 16 | | Sigma Tau Rare Diseases | 2 | 11586.7 |
| 17 | | Syner-Med | 1 | 0.0 |
| 18 | | Thea | 1 | 0.0 |
| 19 | | Vifor Pharma Group | 3 | 729868.4 |
| 20 | | Meda | 1 | 0.0 |
| 21 | | ALK-Abello | 1 | 0.0 |
| 22 | | Bausch and Lomb | 1 | 0.0 |
| 23 | | Genzyme | 12 | 348335.0 |
| 24 | | HRA Pharma | 1 | 0.0 |
| 25 | | BioMarin | 4 | 5000.0 |
| 26 | | Allergan | 5 | 0.0 |
| 27 | | Napp Pharmaceuticals | 2 | 23000.0 |
| 28 | | Amdipharm | 1 | 500.0 |
| 29 | | Alexion | 4 | 27000.0 |
| 30 | | Orphan Europe | 1 | 0.0 |
| 31 | | Ferring | 6 | 0.0 |
| 32 | 2016 | Britannia | 1 | 3884.0 |
| 33 | | Aegerion | 1 | 0.0 |
| 34 | | Baxalta | 1 | 0.0 |
| 35 | | Diurnal | 1 | 0.0 |
| 36 | | PTC | 1 | 0.0 |
| 37 | | Bio Products Laboratory | 1 | 10000.0 |
| 38 | | Octapharma | 2 | 24766.0 |
| 39 | | Sigma Tau Rare Diseases | 1 | 12706.0 |
| 40 | | Baxter | 1 | 16784.0 |
| 41 | | Fresenius Medical Care | 1 | 3000.0 |
| 42 | | Jazz | 1 | 0.0 |
| 43 | | Mylan | 1 | 0.0 |
| 44 | | Dermal | 2 | 0.0 |
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Web Supplement 9. Donors - payments missing from industry data (breakdown for all years)

| Year | Drug company name | Number of payments | Value of payments (2016 £) |
|-----------|--------------------------|--------------------|----------------------------|
| 2012-2016 | RB | 4 | 144270.0 |
| | Genzyme | 52 | 1225894.6 |
| | Sigma Tau Rare Diseases | 8 | 53676.1 |
| | Veriton | 4 | 0.0 |
| | Sanofi Pasteur MSD | 2 | 20989.1 |
| | Fresenius Medical Care | 3 | 15940.6 |
| | Dermal | 13 | 0.0 |
| | Pharma Mar | 2 | 6312.5 |
| | ApoPharma | 5 | 76194.8 |
| | Amdipharm | 4 | 34433.3 |
| | Orphan Europe | 3 | 1028.5 |
| | Gedeon Richter | 2 | 0.0 |
| | PTC | 6 | 0.0 |
| | IQVIA | 1 | 0.0 |
| | Britannia | 4 | 3884.0 |
| | Bausch and Lomb | 4 | 22627.3 |
| | Syner-Med | 3 | 0.0 |
| | Mitsubishi Tanabe Pharma | 1 | 5070.3 |
| | Alliance | 1 | 0.0 |
| | ALK-Abello | 2 | 0.0 |
| | Thea | 1 | 0.0 |
| | Diurnal | 1 | 0.0 |
| | Jazz | 1 | 0.0 |
| | Mylan | 1 | 0.0 |

Web Supplement 10. Donors - summary of payments missing from patient**Year Number of companies missing from patient organ**

| | |
|-------------|---|
| 2012 | 5 |
| 2013 | 3 |
| 2014 | 7 |
| 2015 | 5 |
| 2016 | 4 |

Total missing - calculate N/A**Total missing - calculate 3**

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it organisation data**Companies missing from patient organisation data as a share of companies in**

8.9%

4.6%

10.8%

7.1%

6.2%

N/A**3.6%**

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Number of payments missing from patient organisa Number of payments missing from patient organisa

| | |
|-----------|-------------|
| 14 | 4.8% |
| 6 | 1.8% |
| 17 | 4.9% |
| 20 | 5.5% |
| 10 | 3.0% |
| 67 | 4.0% |
| 9 | 0.5% |

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|------------------|-------------|
| 113,328.0 | 3.3% |
| 68,397.8 | 1.5% |
| 138,893.5 | 2.6% |
| 52,758.7 | 1.1% |
| 20,649.1 | 0.1% |
| 394,027.2 | 1.2% |
| 92,208.2 | 0.3% |

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on data as a share of payments in patient organisation data

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Web Supplement 11. Donors - payments missing from patient organisation data (yearly break

| Year | Drug company name | Number of payments | Value of payments (2016 £) |
|------|--------------------------|--------------------|----------------------------|
| 2012 | A. Menarini | 2 | 26302.1 |
| | Consilient Health | 2 | 21041.7 |
| | Daiichi Sankyo | 2 | 16833.3 |
| | Meda | 4 | 30589.3 |
| | Servier Laboratories | 4 | 18561.6 |
| 2013 | Consilient Health | 1 | 10285.1 |
| | HRA Pharma | 3 | 46797.4 |
| | Servier Laboratories | 2 | 11315.4 |
| | A. Menarini | 1 | 7605.4 |
| | Almirall | 3 | 47559.2 |
| 2014 | Chugai | 2 | 811.2 |
| | Consilient Health | 1 | 10140.6 |
| | Grünenthal | 3 | 12939.4 |
| | Lundbeck | 5 | 50702.8 |
| | Servier Laboratories | 2 | 9134.9 |
| | Almirall | 3 | 12538.1 |
| 2015 | Chugai | 2 | 15409.9 |
| | Flynn Pharma | 5 | 13700.7 |
| | Rosemont Pharmaceuticals | 7 | 0.0 |
| | Stirling Anglian | 3 | 11110.0 |
| | Almirall | 3 | 2871.6 |
| 2016 | Chugai | 3 | 2612.5 |
| | Flynn Pharma | 3 | 5165.0 |
| | Orion Pharma | 1 | 10000.0 |

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Web Supplement 12. Donors - payments missing from patient organisation data (all years)

| Year | Drug company name | Number of payments | Value of payments (2016 £) |
|-----------|-------------------|--------------------|----------------------------|
| | A. Menarini | 3 | 33907.5 |
| 2012-2016 | Consilient Health | 4 | 41467.4 |
| | Daiichi Sankyo | 2 | 16833.3 |

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Web Supplement 13. Recipients - summary of payments missing from patient organisatio

| Year | Number of patient organisations missing from pa |
|---|---|
| 2012 | 116 |
| 2013 | 123 |
| 2014 | 131 |
| 2015 | 141 |
| 2016 | 143 |
| Total missing - calculated annually | N/A |
| Total missing - calculated for all years | 225 |

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in data

Patient organisations missing from patient organisation data as a share of all

112.6%
120.6%
112.9%
111.9%
122.2%

N/A
112.5%

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Number of payments missing from patient orga Number of payments missing from patient orga

| | |
|-------------|---------------|
| 399 | 137.1% |
| 369 | 113.2% |
| 411 | 118.8% |
| 462 | 128.0% |
| 533 | 158.2% |
| 2174 | 130.9% |
| 1472 | 88.6% |

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|----------------------|--------------|
| 3,659,293.41 | 105.8% |
| 2,340,576.29 | 53.0% |
| 4,427,502.34 | 83.5% |
| 6,591,354.62 | 136.6% |
| 4,871,241.58 | 32.4% |
| 21,889,968.23 | 66.3% |
| 14,023,475.41 | 42.4% |

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Table 14. Recipients - payments missing from patient organisation data (yearly breakdown)**Patient organisation name**

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5 Action on Pre-Eclampsia
6 African-Caribbean Leukaemia Trust
7 Age Related Diseases and Health Trust
8 Allergy Research Foundation
9 Alzheimer Scotland
10 Alzheimers Dementia Support
11 Anaphylaxis Campaign
12 Anticoagulation UK
13 Arrhythmia Alliance
14 Arthritis and Musculoskeletal Alliance
15 Atrial Fibrillation Association
16 Beating Bowel Cancer
17 Bipolar Scotland
18 Bipolar UK
19 Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
20 Bladder Health UK
21 Blood Pressure UK
22 Bluebell Foundation
23 Brain Charity
24 Breakthrough Breast Cancer (current name Breast Cancer Now, following merger with Breast Cancer Campaign)
25 Breast Cancer Campaign (current name Breast Cancer Now, following merger with Breakthrough Breast Cancer)
26 British Dupuytren's Society
27 British Heart Foundation
28 British Obesity Society
29 Brook
30 Cancer 52
31 Cancer Focus Northern Ireland
32 Cancer Research UK
33 Child Growth Foundation
34 Children with Cancer UK
35 Children's Heart Unit Fund
36 Children's HIV Association
37 Chinese National Healthy Living Centre
38 Cleft Lip and Palate Association
39 Coping with Cancer in Leicestershire and Rutland
40 Core Charity
41 Crohn's in Childhood Research Association
42 Cure Parkinson's Trust
43 Cystic Fibrosis Trust
44 Deaf Education through Listening and Talking
45 Diabetes Research and Wellness Foundation
46 Diabetes UK
47 Disabled Living
48 Epilepsy Scotland
49 European Parkinson's Disease Association
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2 Family Planning Association
3 Forum Link
4 Gay Men's Health
5 GIST Support UK
6 Group B Strep Support UK
7 Haemophilia Society
8 Health and Social Care Alliance Scotland
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10 Heartbeat
11 Hereditary Angioedema UK
12 HIV i-Base
13 Hughes Syndrome Foundation
14 ICUsteps
15 Independent Cancer Patients' Voice
16 International Alliance of Patients' Organizations
17 Karen Clifford Skcin cancer charity
18 Kidney Cancer UK
19 Leicestershire AIDS Support Services
20 Macmillan Cancer Support
21 Maggie's Centre
22 Malnutrition and Nutritional Care in the UK
23 Marie Curie Cancer Care
24 Medical Foundation for HIV and Sexual Health
25 Melanoma UK
26 Mental Health Foundation
27 Migraine Action
28 MPN Voice
29 Myeloma UK
30 Myrovlytis Trust
31 National Eczema Society
32 National Kidney Federation
33 National Obesity Forum
34 National Osteoporosis Society
35 OcuMel UK
36 Organisation for Sickle Cell Anaemia Research and Thalassaemia Support
37 Paget's Association
38 Pain Association Scotland
39 Pain Concern
40 Pain Relief Foundation
41 Pain UK
42 Pancreatic Cancer UK
43 Patients Association
44 Pelvic Pain Support Network
45 Positive East
46 Prader-Willi Syndrome Association UK
47 Prostate Cancer Research Centre
48 QUIT
49 Rarer Cancers Foundation
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51 Raynaud's and Scleroderma Association (current name: Scleroderma and Raynauds UK, following the merger

1
2 Richmond Fellowship
3 Roy Castle Lung Cancer Foundation
4 Salamander Trust
5 SANE
6 SeeAbility
7 Service by Emergency Response Volunteers - Suffolk and Cambridgeshire
8 Shift.MS
9 Silver Star
10 Society for Mucopolysaccharide Diseases
11 Somerville Foundation
12 Spinal Injuries Scotland
13 Spinal Muscular Atrophy Support UK
14 Stroke Association
15 Tackle Prostate Cancer
16 Tenovus Cancer Care
17 Thames Valley Positive Support
18 Thrombosis UK
19 Trigeminal Neuralgia Association
20 UK Gout Society
21 UK Primary Immune-deficiency Patient Support
22 Waverley Care
23 World Child Cancer
24 21 and Co
25 Action on Pain
26 Action on Smoking and Health - Scotland
27 ADHD Foundation
28 African-Caribbean Leukaemia Trust
29 African's Getting Involved
30 Alpha-1 Awareness UK
31 Alpha-1 UK Support Group
32 Anaphylaxis Campaign
33 Anticoagulation UK
34 Arrhythmia Alliance
35 Arthritis and Musculoskeletal Alliance
36 Association for Glycogen Storage Disease
37 Association for Multiple Endocrine Neoplasia Disorders
38 Atrial Fibrillation Association
39 Barts and The London Charity
40 Beating Bowel Cancer
41 Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
42 Bladder Health UK
43 Bloodwise
44 Bowel Cancer UK
45 Breakthrough Breast Cancer (current name Breast Cancer Now, following merger with Breast Cancer Campaign)
46 Breast Cancer Haven (The Haven)
47 British Dupuytren's Society
48 British Heart Foundation
49 British Liver Trust
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1 British Polio Fellowship
2 Brittle Bone Society
3 Brook
4 Cancer 52
5 Cancer Research UK
6 Cardiac Risk in the Young
7 Cardiomyopathy UK
8 Cleft Lip and Palate Association
9 Coeliac UK
10 Community Cancer Centre
11 Contact a Family
12 Crohn's in Childhood Research Association
13 Cure Parkinson's Trust
14 Cystic Fibrosis Trust
15 David Lewis Centre
16 Dementia UK
17 Diabetes Research and Wellness Foundation
18 Douglas Bader Foundation
19 Epilepsy Connections
20 Epilepsy Scotland
21 Family Planning Association
22 Forum Link
23 Gauchers Association
24 Gay Men's Health
25 Haemophilia Scotland
26 Haemophilia Society
27 Heart UK
28 Hereditary Angioedema UK
29 HIV i-Base
30 ICUsteps
31 Independent Cancer Patients' Voice
32 International Alliance of Patients' Organizations
33 Juvenile Diabetes Research Foundation
34 Kidney Cancer Support Network
35 Kidney Cancer UK
36 Leicestershire AIDS Support Services
37 Life Education Wessex
38 Liver4Life
39 Lupus Europe
40 Macmillan Cancer Support
41 Maggie's Centre
42 Marie Curie Cancer Care
43 Melanoma UK
44 Men's Health Forum
45 Mesothelioma UK
46 MPN Voice
47 Myeloma UK
48 National AIDS Manual

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2 National Eczema Society
3 National Kidney Federation
4 National Obesity Forum
5 National Osteoporosis Society
6 Northern Ireland Chest, Heart and Stroke
7 OcuMel UK
8 Oliver King Foundation
9 Orchid
10 Organisation for Sickle Cell Anaemia Research and Thalassaemia Support
11 Ovacome
12 Ovarian Cancer Action
13 Pain Association Scotland
14 Pain Concern
15 Pain UK
16 Pancreatic Cancer Action
17 Pancreatic Cancer UK
18 Parkinson's UK
19 Patients Association
20 PBC Foundation UK
21 Polycystic Kidney Disease Charity
22 Positive East
23 Prostate Cancer Support Organisation
24 Prostate Cancer UK (merged with Prostate Action in 2012, retaining its original name)
25 Pumping Marvellous Foundation
26 QUIT
27 Rarer Cancers Foundation
28 Restless Leg Syndrome UK
29 Ronald McDonald House Charities
30 Roy Castle Lung Cancer Foundation
31 Royal Free Charity
32 SANE
33 Sarcoma UK
34 Scoliosis Association UK
35 Scotland Patients Association
36 Scottish Epilepsy Initiative
37 Self Help Services
38 Shift.MS
39 Silver Star
40 South Asian Health Foundation
41 SUDEP Action
42 Target Ovarian Cancer
43 Tenovus Cancer Care
44 Thrombosis UK
45 Transplant Links
46 Trigeminal Neuralgia Association
47 UK Primary Immune-deficiency Patient Support
48 UK Sepsis Trust
49 Waverley Care
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1 World Child Cancer
2 AADC Research Trust
3 Action Duchenne
4 Action for Pulmonary Fibrosis
5 Action on Pain
6 Action on Smoking and Health - Wales
7 Actionplus Foundation
8 Addaction
9 Addenbrooks Charitable Trust
10 African Health Policy Network
11 African-Caribbean Leukaemia Trust
12 Alcohol Concern
13 Alpha-1 UK Support Group
14 Anaphylaxis Campaign
15 Anticoagulation UK
16 Arrhythmia Alliance
17 Arthritis and Musculoskeletal Alliance
18 Arthritis Research UK
19 Association for Glycogen Storage Disease
20 Asthma and Allergy Foundation
21 Asthma Relief
22 Atrial Fibrillation Association
23 Basil Skyers Myeloma Foundation
24 Beating Bowel Cancer
25 Behcets Syndrome Society
26 Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
27 Bloodwise
28 Bone Cancer Research Trust
29 Brain Tumor Charity
30 Breast Cancer Campaign (current name Breast Cancer Now, following merger with Breakthrough Breast Canc
31 Breast Cancer Haven (The Haven)
32 British Dupuytren's Society
33 British Heart Foundation
34 British Liver Trust
35 British Pregnancy Advisory Service
36 British Skin Foundation
37 Brook
38 Building for the Future
39 Cancer 52
40 Cancer Focus Northern Ireland
41 Cancer Research UK
42 Catholics for AIDS Prevention and Support
43 Child Growth Foundation
44 Children with Cancer in Malawi
45 Chronic Lymphocytic Leukaemia Support Association
46 Contact a Family
47 Core Charity
48 Crohn's in Childhood Research Association

1
2 Cure Parkinson's Trust
3 Cystic Fibrosis Trust
4 Diabetes Research and Wellness Foundation
5 Disabled Living
6 Edinburgh and Lothian Prostate Cancer Support Group
7 Epilepsy Connections
8 Epilepsy Scotland
9 European Parkinson's Disease Association
10 Family Planning Association
11 Food Chain
12 FORCE
13 Forum Link
14 Freshwinds
15 Gay Men's Health
16 Haemophilia Society
17 Heart UK
18 Hepatitis B Positive Trust
19 HIV i-Base
20 Independent Cancer Patients' Voice
21 Juvenile Diabetes Research Foundation
22 Karen Clifford Skcin cancer charity
23 Kidney Cancer Support Network
24 Kidney Cancer UK
25 Leukaemia CARE
26 Liver4Life
27 Make A Wish Foundation
28 Melanoma UK
29 Mental Health Foundation
30 Mesothelioma UK
31 Migraine Action
32 MPN Voice
33 Multi Organ Transplant Support
34 National AIDS Manual
35 National Association for Pre-Menstrual Syndrome
36 National Eczema Society
37 National Kidney Federation
38 National Osteoporosis Society
39 Niemann-Pick UK
40 North of England Bone Marrow and Thalassaemia Association
41 Northern Ireland Rare Disease Partnership
42 Orchid
43 Ovacome
44 Ovarian Cancer Action
45 Paget's Association
46 Pain Concern
47 Pain UK
48 Pancreatic Cancer UK
49 Parkinson's UK
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1 Patients Association
2 PBC Foundation UK
3 Polycystic Kidney Disease Charity
4 Positive East
5 Prostate Cancer Support Organisation
6 Prostate Cancer UK (merged with Prostate Action in 2012, retaining its original name)
7 Prostate Cymru
8 Rainbow Centre for Conductive Education
9 Rapid Effective Assistance For Children With Potentially Terminal Illness
10 Rarer Cancers Foundation
11 Raynaud's and Scleroderma Association (current name: Scleroderma and Raynauds UK, following the merger
12 Release
13 Restless Leg Syndrome UK
14 Revive Multiple Sclerosis Support
15 Roy Castle Lung Cancer Foundation
16 Royal Marsden Cancer Charity
17 Royal National Institute of Blind People
18 SANE
19 Sarcoma UK
20 Scleroderma Society (current name: Scleroderma and Raynauds UK, following the merger of Raynaud's and S
21 Scottish Drugs Forum
22 Scottish Epilepsy Initiative
23 Silver Star
24 Skin Care Cymru
25 Sophia Forum
26 St Thomas Lupus Trust
27 Stroke Association
28 SUDEP Action
29 Tackle Prostate Cancer
30 Transplant Links
31 UK Chronic Lymphocytic Leukaemia Forum
32 UK Gout Society
33 UK Primary Immune-deficiency Patient Support
34 Walk the Walk Worldwide
35 Waverley Care
36 World Child Cancer
37 Action Duchenne
38 Action on Pain
39 Addaction
40 ADHD Foundation
41 African Health Policy Network
42 Age UK
43 aHUS UK
44 Alcohol Concern
45 Alpha-1 UK Support Group
46 Anaphylaxis Campaign
47 Angelman Syndrome Support Education Research Trust
48 Anticoagulation UK

1
2 Anxiety UK
3 Aplastic Anaemia Trust
4 Arrhythmia Alliance
5 Arthritis and Musculoskeletal Alliance
6 Association for Glycogen Storage Disease
7 Atrial Fibrillation Association
8 BackCare
9
10 Basil Skyers Myeloma Foundation
11 Beat Parkinson's
12 Beating Bowel Cancer
13 Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
14 Bloodwise
15 Bluebell Foundation
16 Body and Soul
17 Bone Cancer Research Trust
18 Breast Cancer Campaign (current name Breast Cancer Now, following merger with Breakthrough Breast Cancer)
19 Breast Cancer Haven (The Haven)
20 Breast Cancer Now (created after the merger of Breast Cancer Campaign and Breakthrough Breast Cancer in 2017)
21 British Dupuytren's Society
22 British Heart Foundation
23 British Liver Trust
24 British Skin Foundation
25 Brook
26 Cambridge Rare Disease Network
27 Cancer 52
28 Cancer Focus Northern Ireland
29 Cancer Research UK
30 Candlelighters
31 Children with Cancer UK
32 Children's Liver Disease Foundation
33 Chronic Lymphocytic Leukaemia Support Association
34 CLIC Sargent Cancer Care For Children
35 Contact a Family
36 Cure Parkinson's Trust
37 Cystic Fibrosis Trust
38 Delete Blood Cancer
39 Diabetes UK
40 Diabetics with Eating Disorders
41 Diamond Blackfan Anaemia UK
42 Douglas Bader Foundation
43 Encephalitis Society
44 Food Chain
45 Forum Link
46 Freshwinds
47 Friends of FOP
48 Gauchers Association
49 Gay Men's Health
50 Haemophilia Scotland
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1 Haemophilia Society
2 Haemophilia Wales
3 Hidradenitis Suppurativa Trust
4 HIV i-Base
5 Independent Cancer Patients' Voice
6 Input Diabetes
7 International Chronic Myeloid Leukemia Foundation
8 Karen Clifford Skin cancer charity
9 Kidney Cancer Support Network
10 Kidney Cancer UK
11 Kidney Care UK
12 LATCH Welsh Children's Cancer Charity
13 Leeds Teaching Hospital Charitable Foundation
14 Little Hearts Matter
15 Liver4Life
16 Lullaby Trust
17 Lupus Europe
18 Lupus UK
19 Macular Society
20 Maggie's Centre
21 MAMA Academy
22 Melanoma UK
23 Mental Health Foundation
24 Mesothelioma UK
25 Movember Foundation
26 Multiple Births Foundation
27 Myasthenia Gravis Association
28 NARA - The Breathing Charity
29 National AIDS Manual
30 National Eczema Society
31 National Kidney Federation
32 National Osteoporosis Society
33 NMO Research Foundation
34 North of England Bone Marrow and Thalassaemia Association
35 Older People's Advocacy Alliance
36 Ovacome
37 Pancreatic Cancer UK
38 Patients Association
39 Patients On Intravenous and Nasogastric Nutrition Therapy
40 Pelvic Pain Support Network
41 Portsmouth Down Syndrome Association
42 Positive Action
43 Progressive Supranuclear Palsy Association
44 Prostate Cancer UK (merged with Prostate Action in 2012, retaining its original name)
45 QUIT
46 Rainbow Trust Children's Charity
47 Rapid Effective Assistance For Children With Potentially Terminal Illness
48 Rarer Cancers Foundation

- 1
- 2 Raynaud's and Scleroderma Association (current name: Scleroderma and Raynauds UK, following the merger
- 3 Restless Leg Syndrome UK
- 4 Rethink Mental Illness
- 5 River House Trust
- 6
- 7 Roy Castle Lung Cancer Foundation
- 8 Royal Free Charity
- 9 Royal National Institute of Blind People
- 10 Salamander Trust
- 11
- 12 SANE
- 13 Scleroderma Society (current name: Scleroderma and Raynauds UK, following the merger of Raynaud's and S
- 14 Scottish Kidney Federation
- 15 Sense
- 16
- 17 Silver Star
- 18 Skin Care Cymru
- 19 Sophia Forum
- 20
- 21 Spectra
- 22 Spinal Injuries Association
- 23 St Thomas Lupus Trust
- 24 Steps
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- 26 Stroke Association
- 27 Tackle Prostate Cancer
- 28 TB Alert
- 29
- 30 Team Margot
- 31 Teenage Cancer Trust
- 32 Tenovus Cancer Care
- 33
- 34 Thrombosis UK
- 35 Transverse Myelitis Society
- 36
- 37 Tree of Hope
- 38 UK Primary Immune-deficiency Patient Support
- 39
- 40 UK Thalassaemia Society
- 41 Waverley Care
- 42
- 43 World Child Cancer
- 44 York Air Ambulance
- 45
- 46 Action Bladder Cancer UK
- 47
- 48 Action Duchenne
- 49
- 50 Action on Smoking and Health - Wales
- 51
- 52 Actionplus Foundation
- 53
- 54 Addaction
- 55
- 56 ADHD Foundation
- 57
- 58 African-Caribbean Leukaemia Trust
- 59
- 60 ALD Life
- 61
- 62 Allergy UK
- 63
- 64 Alpha-1 UK Support Group
- 65
- 66 Ankylosing Spondylitis International Federation
- 67
- 68 Anthony Nolan
- 69
- 70 Anticoagulation UK
- 71
- 72 Arrhythmia Alliance
- 73
- 74 Arthritis and Musculoskeletal Alliance

1 Asyabi UK
2 Atrial Fibrillation Association
3 Back on Track
4 BackCare
5 Basil Skyers Myeloma Foundation
6 Beating Bowel Cancer
7 Birdshot Uveitis Society
8 Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
9 Body and Soul
10 Brain Tumour Research
11 Breast Cancer Haven (The Haven)
12 British Dupuytren's Society
13 British Liver Trust
14 British Skin Foundation
15 Brook
16 Cambridge Rare Disease Network
17 Cancer 52
18 Cancer Focus Northern Ireland
19 Cancer Research UK
20 Cardiac Risk in the Young
21 Cardiomyopathy UK
22 Charlie Waller Memorial Trust
23 Child Growth Foundation
24 Children's Liver Disease Foundation
25 Chronic Lymphocytic Leukaemia Support Association
26 CLIC Sargent Cancer Care For Children
27 Coppafeel!
28 Crohn's in Childhood Research Association
29 Cure and Action for Tay-Sachs
30 Cure Parkinson's Trust
31 Cystic Fibrosis Trust
32 Delete Blood Cancer
33 Diabetes UK
34 Diabetics with Eating Disorders
35 Different Strokes
36 Disabled Living
37 Encephalitis Society
38 Epilepsy Action
39 Epilepsy Scotland
40 Family Planning Association
41 Foundation for Liver Research
42 GIST Support UK
43 Guillain Barre and associated inflammatory neuropathies
44 Haemophilia Scotland
45 Haemophilia Society
46 Haemophilia Wales
47 Hafal
48 Headway

1 Heart UK
2 HIV i-Base
3 HIV Scotland
4 Imperial College Healthcare Charity
5 Independent Cancer Patients' Voice
6 Juvenile Diabetes Research Foundation
7 KAITY
8 Karen Clifford Skcin cancer charity
9 Kidney Cancer Support Network
10 Kidney Cancer UK
11 Kidney Care UK
12 Liver4Life
13 Lupus Europe
14 Macmillan Cancer Support
15 Make A Wish Foundation
16 Marie Curie Cancer Care
17 Martin Fisher Foundation
18 MDS UK Support Group
19 Melanoma Focus
20 Melanoma Fund
21 Melanoma UK
22 Mesothelioma UK
23 Migraine Action
24 Motor Neurone Disease Association
25 MPN Voice
26 Multiple Sclerosis UK
27 Muscular Dystrophy UK
28 National Attention Deficit Disorder Information and Support Service
29 National Cancer Research Institute
30 National Childbirth Trust
31 National Eczema Society
32 National Kidney Federation
33 National Osteoporosis Society
34 National Rheumatoid Arthritis Society
35 NMO Research Foundation
36 Northern Ireland Rare Disease Partnership
37 Olive Tree Cancer Support Centre - Crawley
38 Ovacome
39 Ovarian Cancer Action
40 Paget's Association
41 Pain Concern
42 Pancreatic Cancer Action
43 Parkinson's UK
44 Patients Association
45 Patients On Intravenous and Nasogastric Nutrition Therapy
46 Paula Carr Diabetes Trust
47 Pelican Cancer Foundation
48 Pink Ribbon Foundation – Breast Cancer Charity

1 Polycystic Kidney Disease Charity
2 Progressive Supranuclear Palsy Association
3 QUIT
4 Rarer Cancers Foundation
5 Restless Leg Syndrome UK
6 Roy Castle Lung Cancer Foundation
7 Royal National Institute of Blind People
8 Samson Centre for MS
9 SANE
10 Sarcoma UK
11 Save Babies Through Screening Foundation UK
12 Scleroderma and Raynauds UK (established following the merger of Raynaud's and Scleroderma Association a
13 Scottish Network Children with Arthrities
14 Sexual Advice Association
15 Short Bowel Survivor and Friends
16 Skin Care Cymru
17 Somerville Foundation
18 Sussex Beacon
19 Tackle Prostate Cancer
20 Teenage Cancer Trust
21 Tenovus Cancer Care
22 Thames Valley Positive Support
23 Thrombosis UK
24 Tuberos Sclerosis Association
25 Visionary
26 Waldenstroms Macroglobulinaemia UK
27 Waverley Care
28 WellChild
29 Willow Foundation
30 World Cancer Research Fund
31 World Child Cancer
32 Young Epilepsy
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| | Number of payments | Value of payments (2016 £) |
|----|---------------------------|-----------------------------------|
| 1 | | |
| 2 | | |
| 3 | | |
| 4 | 3 | 3488.9 |
| 5 | 1 | 10520.8 |
| 6 | 1 | 15781.3 |
| 7 | 1 | 15781.3 |
| 8 | 2 | 39258.9 |
| 9 | 2 | 21041.7 |
| 10 | 2 | 563.6 |
| 11 | 2 | 563.6 |
| 12 | 1 | 1057.3 |
| 13 | 1 | 15860.2 |
| 14 | 1 | 15860.2 |
| 15 | 12 | 20260.5 |
| 16 | 6 | 7381.0 |
| 17 | 5 | 37832.9 |
| 18 | 36 | 227017.3 |
| 19 | 5 | 36010.8 |
| 20 | 3 | 3193.8 |
| 21 | 3 | 3193.8 |
| 22 | 3 | 4145.2 |
| 23 | 13 | 415672.2 |
| 24 | 7 | 6165.9 |
| 25 | 7 | 6165.9 |
| 26 | 1 | 10520.8 |
| 27 | 1 | 473.4 |
| 28 | 1 | 981.5 |
| 29 | 2 | 5298.0 |
| 30 | 2 | 5298.0 |
| 31 | 1 | 6312.5 |
| 32 | 2 | 599.7 |
| 33 | 1 | 117.8 |
| 34 | 1 | 420.8 |
| 35 | 4 | 33929.7 |
| 36 | 4 | 33929.7 |
| 37 | 5 | 33140.6 |
| 38 | 3 | 5681.3 |
| 39 | 10 | 660846.1 |
| 40 | 1 | 1578.1 |
| 41 | 1 | 1578.1 |
| 42 | 1 | 473.4 |
| 43 | 1 | 736.5 |
| 44 | 1 | 7890.6 |
| 45 | 1 | 7890.6 |
| 46 | 1 | 252.5 |
| 47 | 1 | 58.9 |
| 48 | 1 | 4187.3 |
| 49 | 1 | 8416.7 |
| 50 | 1 | 8416.7 |
| 51 | 3 | 12625.0 |
| 52 | 1 | 254.6 |
| 53 | 2 | 12650.6 |
| 54 | 1 | 526.0 |
| 55 | 1 | 526.0 |
| 56 | 1 | 2104.2 |
| 57 | 29 | 315722.5 |
| 58 | 1 | 5260.4 |
| 59 | 1 | 37.6 |
| 60 | 1 | 21362.0 |

| | | |
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| 1 | | |
| 2 | 3 | 7680.2 |
| 3 | 2 | 747.0 |
| 4 | 3 | 9153.1 |
| 5 | 4 | 12414.6 |
| 6 | 1 | 153.6 |
| 7 | 9 | 50719.9 |
| 8 | 1 | 37.6 |
| 9 | 1 | 757.5 |
| 10 | 3 | 24923.9 |
| 11 | 4 | 16970.1 |
| 12 | 1 | 2104.2 |
| 13 | 1 | 2099.5 |
| 14 | 2 | 4103.1 |
| 15 | 3 | 122044.1 |
| 16 | 1 | 10520.8 |
| 17 | 8 | 24125.3 |
| 18 | 2 | 925.8 |
| 19 | 5 | 19768.6 |
| 20 | 1 | 157.8 |
| 21 | 1 | 883.8 |
| 22 | 1 | 241.4 |
| 23 | 1 | 5260.4 |
| 24 | 2 | 21041.7 |
| 25 | 2 | 79095.6 |
| 26 | 2 | 25776.0 |
| 27 | 2 | 18170.9 |
| 28 | 7 | 215976.6 |
| 29 | 1 | 1420.3 |
| 30 | 9 | 20541.9 |
| 31 | 8 | 144188.0 |
| 32 | 2 | 1157.3 |
| 33 | 3 | 13082.8 |
| 34 | 1 | 1052.1 |
| 35 | 1 | 2104.2 |
| 36 | 1 | 2104.2 |
| 37 | 4 | 3000.9 |
| 38 | 4 | 6689.5 |
| 39 | 1 | 631.3 |
| 40 | 4 | 16916.6 |
| 41 | 1 | 8416.7 |
| 42 | 10 | 66089.5 |
| 43 | 3 | 1188.0 |
| 44 | 1 | 16496.7 |
| 45 | 1 | 473.4 |
| 46 | 1 | 1052.1 |
| 47 | 7 | 19502.5 |
| 48 | 16 | 134019.4 |
| 49 | 5 | 5946.4 |

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| 1 | | |
| 2 | 1 | 736.5 |
| 3 | 11 | 136368.8 |
| 4 | 1 | 417.7 |
| 5 | 1 | 1052.1 |
| 6 | 1 | 473.4 |
| 7 | 1 | 210.4 |
| 8 | 1 | 2865.9 |
| 9 | 1 | 2865.9 |
| 10 | 4 | 40505.2 |
| 11 | 4 | 40505.2 |
| 12 | 14 | 161724.0 |
| 13 | 2 | 6327.7 |
| 14 | 1 | 1052.1 |
| 15 | 1 | 26302.1 |
| 16 | 1 | 26302.1 |
| 17 | 3 | 4771.9 |
| 18 | 1 | 5260.4 |
| 19 | 1 | 45554.2 |
| 20 | 1 | 736.5 |
| 21 | 1 | 736.5 |
| 22 | 5 | 19805.5 |
| 23 | 2 | 4208.3 |
| 24 | 1 | 10520.8 |
| 25 | 2 | 5643.4 |
| 26 | 2 | 5643.4 |
| 27 | 2 | 9021.6 |
| 28 | 2 | 16096.9 |
| 29 | 1 | 1028.5 |
| 30 | 6 | 5139.5 |
| 31 | 6 | 5139.5 |
| 32 | 1 | 2519.9 |
| 33 | 1 | 205.7 |
| 34 | 1 | 18513.2 |
| 35 | 1 | 129.6 |
| 36 | 1 | 129.6 |
| 37 | 2 | 16456.2 |
| 38 | 2 | 15942.0 |
| 39 | 1 | 25712.8 |
| 40 | 1 | 25712.8 |
| 41 | 20 | 73150.1 |
| 42 | 6 | 78372.7 |
| 43 | 5 | 52570.4 |
| 44 | 1 | 2057.0 |
| 45 | 1 | 0.0 |
| 46 | 1 | 0.0 |
| 47 | 20 | 108390.1 |
| 48 | 1 | 205.7 |
| 49 | 5 | 30968.5 |
| 50 | 5 | 30968.5 |
| 51 | 2 | 21418.9 |
| 52 | 3 | 8377.2 |
| 53 | 1 | 236.7 |
| 54 | 1 | 10285.1 |
| 55 | 1 | 10285.1 |
| 56 | 6 | 29896.9 |
| 57 | 1 | 771.4 |
| 58 | 3 | 2611.4 |
| 59 | 3 | 742.3 |
| 60 | 2 | 15633.4 |

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| 1 | | |
| 2 | 1 | 0.0 |
| 3 | 1 | 15427.7 |
| 4 | 3 | 23347.3 |
| 5 | 4 | 32912.4 |
| 6 | 4 | 32912.4 |
| 7 | 9 | 33791.8 |
| 8 | 1 | 462.8 |
| 9 | 1 | 518.7 |
| 10 | 1 | 62.0 |
| 11 | 1 | 62.0 |
| 12 | 1 | 129.6 |
| 13 | 1 | 1028.5 |
| 14 | 1 | 7713.8 |
| 15 | 2 | 7207.8 |
| 16 | 2 | 3983.1 |
| 17 | 2 | 3983.1 |
| 18 | 3 | 1016.7 |
| 19 | 1 | 1892.5 |
| 20 | 1 | 2592.9 |
| 21 | 1 | 2057.0 |
| 22 | 1 | 2057.0 |
| 23 | 1 | 778.1 |
| 24 | 1 | 2057.0 |
| 25 | 1 | 1285.6 |
| 26 | 1 | 1285.6 |
| 27 | 4 | 41449.1 |
| 28 | 2 | 5425.4 |
| 29 | 6 | 23100.4 |
| 30 | 2 | 2879.8 |
| 31 | 2 | 2879.8 |
| 32 | 4 | 6428.2 |
| 33 | 5 | 65192.3 |
| 34 | 25 | 188350.6 |
| 35 | 4 | 40673.6 |
| 36 | 4 | 40673.6 |
| 37 | 4 | 16263.9 |
| 38 | 1 | 2057.0 |
| 39 | 1 | 3085.5 |
| 40 | 3 | 76571.8 |
| 41 | 3 | 76571.8 |
| 42 | 4 | 51906.0 |
| 43 | 1 | 48032.0 |
| 44 | 3 | 32912.4 |
| 45 | 2 | 21290.2 |
| 46 | 2 | 21290.2 |
| 47 | 1 | 518.7 |
| 48 | 1 | 360.0 |
| 49 | 1 | 8733.1 |
| 50 | 1 | 8733.1 |
| 51 | 7 | 21486.0 |
| 52 | 1 | 2809.2 |
| 53 | 1 | 251.5 |
| 54 | 3 | 19582.9 |
| 55 | 2 | 5130.7 |
| 56 | 2 | 5130.7 |
| 57 | 2 | 10626.4 |
| 58 | 1 | 1028.5 |
| 59 | 8 | 207709.3 |
| 60 | 4 | 23005.8 |

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| 1 | | |
| 2 | 2 | 2327.5 |
| 3 | 7 | 62885.3 |
| 4 | 1 | 2351.2 |
| 5 | 8 | 22156.9 |
| 6 | 1 | 1028.5 |
| 7 | 1 | 1028.5 |
| 8 | 1 | 1028.5 |
| 9 | 1 | 510.9 |
| 10 | 1 | 3085.5 |
| 11 | 1 | 2079.9 |
| 12 | 1 | 2079.9 |
| 13 | 2 | 5656.8 |
| 14 | 1 | 10285.1 |
| 15 | 6 | 1635.3 |
| 16 | 5 | 5471.7 |
| 17 | 3 | 6582.5 |
| 18 | 1 | 771.4 |
| 19 | 1 | 8228.1 |
| 20 | 1 | 8228.1 |
| 21 | 3 | 8964.6 |
| 22 | 3 | 8964.6 |
| 23 | 9 | 61969.6 |
| 24 | 1 | 475.1 |
| 25 | 2 | 9745.2 |
| 26 | 2 | 9745.2 |
| 27 | 2 | 579.1 |
| 28 | 1 | 1626.1 |
| 29 | 4 | 3594.9 |
| 30 | 2 | 31883.9 |
| 31 | 2 | 31883.9 |
| 32 | 3 | 22722.3 |
| 33 | 3 | 22722.3 |
| 34 | 13 | 122253.9 |
| 35 | 1 | 2571.3 |
| 36 | 1 | 771.4 |
| 37 | 14 | 124200.5 |
| 38 | 1 | 11321.9 |
| 39 | 1 | 20428.5 |
| 40 | 1 | 20428.5 |
| 41 | 1 | 1028.5 |
| 42 | 1 | 277.7 |
| 43 | 1 | 1028.5 |
| 44 | 1 | 1028.5 |
| 45 | 1 | 2571.3 |
| 46 | 2 | 514.3 |
| 47 | 3 | 41140.5 |
| 48 | 6 | 48340.1 |
| 49 | 1 | 35998.0 |
| 50 | 1 | 35998.0 |
| 51 | 1 | 1563.3 |
| 52 | 1 | 0.0 |
| 53 | 1 | 2571.3 |
| 54 | 3 | 14399.2 |
| 55 | 3 | 14399.2 |
| 56 | 1 | 771.4 |
| 57 | 1 | 0.0 |
| 58 | 1 | 0.0 |
| 59 | 4 | 19688.8 |
| 60 | 1 | 19688.8 |
| | 1 | 0.0 |
| | 1 | 4114.1 |

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| 1 | | |
| 2 | 2 | 20914.8 |
| 3 | 1 | 5070.3 |
| 4 | 2 | 3042.2 |
| 5 | 1 | 595.8 |
| 6 | 2 | 4056.2 |
| 7 | 1 | 2028.1 |
| 8 | 1 | 2940.8 |
| 9 | 1 | 2940.8 |
| 10 | 9 | 122041.7 |
| 11 | 1 | 3042.2 |
| 12 | 2 | 20854.0 |
| 13 | 3 | 20857.1 |
| 14 | 4 | 30421.7 |
| 15 | 1 | 60843.4 |
| 16 | 1 | 608.4 |
| 17 | 8 | 60166.5 |
| 18 | 6 | 89084.8 |
| 19 | 9 | 85180.7 |
| 20 | 3 | 583.1 |
| 21 | 1 | 7098.4 |
| 22 | 1 | 507.0 |
| 23 | 1 | 1014.1 |
| 24 | 20 | 86721.7 |
| 25 | 1 | 7098.4 |
| 26 | 8 | 133200.9 |
| 27 | 1 | 20281.1 |
| 28 | 6 | 234694.2 |
| 29 | 3 | 16934.7 |
| 30 | 2 | 10140.6 |
| 31 | 1 | 12675.7 |
| 32 | 5 | 65913.7 |
| 33 | 2 | 12417.3 |
| 34 | 1 | 11465.2 |
| 35 | 2 | 354.9 |
| 36 | 2 | 33463.9 |
| 37 | 1 | 507.0 |
| 38 | 3 | 3549.2 |
| 39 | 3 | 25604.9 |
| 40 | 1 | 243.4 |
| 41 | 5 | 39041.2 |
| 42 | 7 | 10280.6 |
| 43 | 9 | 425099.6 |
| 44 | 1 | 4089.1 |
| 45 | 1 | 1521.1 |
| 46 | 1 | 20179.7 |
| 47 | 1 | 20281.1 |
| 48 | 1 | 7605.4 |
| 49 | 1 | 8112.4 |
| 50 | 1 | 8112.4 |
| 51 | 2 | 7098.4 |
| 52 | 2 | 7098.4 |
| 53 | 1 | 5070.3 |
| 54 | 2 | 3042.2 |
| 55 | 1 | 595.8 |
| 56 | 2 | 4056.2 |
| 57 | 1 | 2028.1 |
| 58 | 1 | 2940.8 |
| 59 | 9 | 122041.7 |
| 60 | 1 | 3042.2 |

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| 1 | | |
| 2 | 2 | 342.6 |
| 3 | 4 | 7250.5 |
| 4 | 1 | 2433.7 |
| 5 | 3 | 17827.1 |
| 6 | 2 | 804.5 |
| 7 | 1 | 2028.1 |
| 8 | 3 | 3442.7 |
| 9 | 2 | 24984.5 |
| 10 | 3 | 22917.7 |
| 11 | 1 | 3042.2 |
| 12 | 1 | 507.0 |
| 13 | 1 | 6084.3 |
| 14 | 1 | 3042.2 |
| 15 | 3 | 11734.7 |
| 16 | 15 | 112989.0 |
| 17 | 18 | 178932.5 |
| 18 | 1 | 5070.3 |
| 19 | 2 | 10647.6 |
| 20 | 1 | 3042.2 |
| 21 | 8 | 205566.7 |
| 22 | 5 | 43874.2 |
| 23 | 1 | 507.0 |
| 24 | 5 | 31800.8 |
| 25 | 8 | 78082.3 |
| 26 | 5 | 59736.0 |
| 27 | 1 | 507.0 |
| 28 | 5 | 133910.2 |
| 29 | 1 | 1216.9 |
| 30 | 1 | 9944.8 |
| 31 | 1 | 33463.9 |
| 32 | 1 | 22682.4 |
| 33 | 1 | 6084.3 |
| 34 | 7 | 82397.2 |
| 35 | 1 | 152.1 |
| 36 | 1 | 304.2 |
| 37 | 6 | 80617.5 |
| 38 | 3 | 77459.8 |
| 39 | 2 | 16267.8 |
| 40 | 3 | 4563.3 |
| 41 | 1 | 2535.1 |
| 42 | 1 | 248.6 |
| 43 | 1 | 10951.8 |
| 44 | 1 | 19267.1 |
| 45 | 1 | 15210.8 |
| 46 | 1 | 3042.2 |
| 47 | 3 | 6601.5 |
| 48 | 9 | 38939.8 |
| 49 | 3 | 6135.0 |

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| 1 | | |
| 2 | 9 | 69674.0 |
| 3 | 2 | 608.4 |
| 4 | 1 | 15210.8 |
| 5 | 1 | 4563.3 |
| 6 | 1 | 461.8 |
| 7 | 1 | 461.8 |
| 8 | 5 | 26839.5 |
| 9 | 1 | 639.6 |
| 10 | 1 | 579.3 |
| 11 | 1 | 579.3 |
| 12 | 1 | 2738.0 |
| 13 | 14 | 194892.6 |
| 14 | 2 | 1139.3 |
| 15 | 1 | 10063.5 |
| 16 | 1 | 10063.5 |
| 17 | 2 | 3338.3 |
| 18 | 1 | 40562.2 |
| 19 | 13 | 179410.6 |
| 20 | 1 | 354.9 |
| 21 | 1 | 354.9 |
| 22 | 9 | 282414.7 |
| 23 | 2 | 26365.5 |
| 24 | 1 | 1014.1 |
| 25 | 1 | 671.8 |
| 26 | 1 | 671.8 |
| 27 | 2 | 4056.2 |
| 28 | 1 | 76054.2 |
| 29 | 1 | 19013.6 |
| 30 | 1 | 19013.6 |
| 31 | 2 | 1014.1 |
| 32 | 1 | 5070.3 |
| 33 | 2 | 835.0 |
| 34 | 9 | 65132.8 |
| 35 | 1 | 770.7 |
| 36 | 1 | 770.7 |
| 37 | 4 | 9011.9 |
| 38 | 1 | 760.5 |
| 39 | 1 | 4056.2 |
| 40 | 1 | 4056.2 |
| 41 | 2 | 27886.5 |
| 42 | 3 | 21428.0 |
| 43 | 1 | 405.6 |
| 44 | 3 | 19058.2 |
| 45 | 7 | 163600.7 |
| 46 | 7 | 163600.7 |
| 47 | 5 | 32262.1 |
| 48 | 1 | 1262.5 |
| 49 | 9 | 189819.4 |
| 50 | 9 | 189819.4 |
| 51 | 3 | 16160.0 |
| 52 | 4 | 10327.3 |
| 53 | 2 | 555.5 |
| 54 | 1 | 25250.0 |
| 55 | 1 | 25250.0 |
| 56 | 6 | 52988.6 |
| 57 | 1 | 60600.0 |
| 58 | 4 | 3030.0 |
| 59 | 1 | 303.0 |
| 60 | 18 | 118527.0 |

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| 1 | | |
| 2 | 1 | 3282.5 |
| 3 | 1 | 1616.0 |
| 4 | 10 | 108324.5 |
| 5 | 8 | 61610.0 |
| 6 | 4 | 18555.7 |
| 7 | 14 | 107478.3 |
| 8 | 1 | 3535.0 |
| 9 | 1 | 18852.7 |
| 10 | 1 | 5050.0 |
| 11 | 9 | 77810.4 |
| 12 | 11 | 1473965.2 |
| 13 | 6 | 40753.5 |
| 14 | 1 | 303.0 |
| 15 | 4 | 57945.7 |
| 16 | 1 | 2020.0 |
| 17 | 1 | 9090.0 |
| 18 | 1 | 19705.1 |
| 19 | 1 | 0.0 |
| 20 | 1 | 31916.0 |
| 21 | 1 | 666.6 |
| 22 | 5 | 17018.5 |
| 23 | 1 | 4155.1 |
| 24 | 1 | 8080.0 |
| 25 | 1 | 1574.6 |
| 26 | 5 | 63630.0 |
| 27 | 2 | 12378.2 |
| 28 | 14 | 662211.6 |
| 29 | 1 | 0.0 |
| 30 | 1 | 151.5 |
| 31 | 1 | 1010.0 |
| 32 | 5 | 47672.0 |
| 33 | 2 | 4559.1 |
| 34 | 1 | 5050.0 |
| 35 | 1 | 10254.5 |
| 36 | 2 | 9595.0 |
| 37 | 2 | 14402.6 |
| 38 | 44 | 899692.9 |
| 39 | 3 | 1347.3 |
| 40 | 1 | 15150.0 |
| 41 | 1 | 606.0 |
| 42 | 1 | 505.0 |
| 43 | 1 | 5050.0 |
| 44 | 1 | 13907.7 |
| 45 | 1 | 8888.0 |
| 46 | 1 | 0.0 |
| 47 | 3 | 19493.0 |
| 48 | 1 | 505.0 |
| 49 | 8 | 13847.3 |

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| 1 | | |
| 2 | 14 | 190024.6 |
| 3 | 5 | 5972.6 |
| 4 | 2 | 6019.6 |
| 5 | 1 | 8080.0 |
| 6 | 2 | 4545.0 |
| 7 | 1 | 30322.2 |
| 8 | 1 | 34105.2 |
| 9 | 3 | 27270.0 |
| 10 | 3 | 20200.0 |
| 11 | 10 | 56661.0 |
| 12 | 1 | 526.2 |
| 13 | 1 | 1010.0 |
| 14 | 1 | 353.5 |
| 15 | 1 | 252.5 |
| 16 | 8 | 131184.9 |
| 17 | 1 | 0.0 |
| 18 | 1 | 25668.1 |
| 19 | 1 | 707.0 |
| 20 | 1 | 15.2 |
| 21 | 1 | 445.9 |
| 22 | 1 | 202.0 |
| 23 | 6 | 124798.6 |
| 24 | 1 | 1212.0 |
| 25 | 1 | 10100.0 |
| 26 | 1 | 1010.0 |
| 27 | 1 | 505.0 |
| 28 | 1 | 2020.0 |
| 29 | 1 | 0.0 |
| 30 | 7 | 47908.3 |
| 31 | 1 | 202.0 |
| 32 | 5 | 61027.2 |
| 33 | 8 | 95647.0 |
| 34 | 1 | 5050.0 |
| 35 | 1 | 1212.0 |
| 36 | 2 | 30300.0 |
| 37 | 2 | 32572.5 |
| 38 | 4 | 122715.0 |
| 39 | 9 | 64371.2 |
| 40 | 1 | 1520.2 |
| 41 | 1 | 1466.7 |
| 42 | 1 | 151.5 |
| 43 | 1 | 0.0 |
| 44 | 1 | 151.5 |
| 45 | 2 | 5302.5 |
| 46 | 2 | 32115.0 |
| 47 | 1 | 1010.0 |
| 48 | 1 | 2462.4 |
| 49 | 10 | 126755.0 |

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| 1 | | |
| 2 | 3 | 20200.0 |
| 3 | 1 | 3030.0 |
| 4 | 1 | 757.5 |
| 5 | 1 | 252.5 |
| 6 | 1 | 252.5 |
| 7 | 14 | 164788.4 |
| 8 | 1 | 505.0 |
| 9 | 7 | 230060.8 |
| 10 | 1 | 303.0 |
| 11 | 1 | 303.0 |
| 12 | 2 | 15840.8 |
| 13 | 2 | 2473.5 |
| 14 | 1 | 505.0 |
| 15 | 1 | 151.5 |
| 16 | 1 | 151.5 |
| 17 | 1 | 10100.0 |
| 18 | 4 | 18060.7 |
| 19 | 1 | 5050.0 |
| 20 | 1 | 1010.0 |
| 21 | 1 | 1010.0 |
| 22 | 1 | 252.5 |
| 23 | 2 | 62115.0 |
| 24 | 1 | 151.5 |
| 25 | 9 | 47571.0 |
| 26 | 9 | 47571.0 |
| 27 | 5 | 83197.3 |
| 28 | 2 | 27401.3 |
| 29 | 1 | 5050.0 |
| 30 | 4 | 3838.0 |
| 31 | 4 | 3838.0 |
| 32 | 4 | 70809.1 |
| 33 | 2 | 2525.0 |
| 34 | 1 | 15150.0 |
| 35 | 1 | 151.5 |
| 36 | 1 | 151.5 |
| 37 | 2 | 20701.0 |
| 38 | 1 | 4040.0 |
| 39 | 5 | 15361.1 |
| 40 | 1 | 50499.9 |
| 41 | 1 | 50499.9 |
| 42 | 1 | 0.0 |
| 43 | 1 | 101.0 |
| 44 | 5 | 11772.1 |
| 45 | 1 | 5000.0 |
| 46 | 1 | 5000.0 |
| 47 | 1 | 5000.0 |
| 48 | 2 | 45000.0 |
| 49 | 4 | 6620.0 |
| 50 | 4 | 6620.0 |
| 51 | 1 | 15000.0 |
| 52 | 1 | 262.3 |
| 53 | 3 | 10160.5 |
| 54 | 1 | 1200.0 |
| 55 | 6 | 38722.8 |
| 56 | 6 | 38722.8 |
| 57 | 1 | 20000.0 |
| 58 | 18 | 103102.5 |
| 59 | 6 | 46355.0 |
| 60 | 5 | 25000.0 |

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| 1 | | |
| 2 | 1 | 1500.0 |
| 3 | 14 | 91536.8 |
| 4 | 1 | 3809.2 |
| 5 | 2 | 4000.0 |
| 6 | 2 | 9250.0 |
| 7 | 2 | 9250.0 |
| 8 | 15 | 64682.6 |
| 9 | 1 | 10000.0 |
| 10 | | |
| 11 | 6 | 125466.9 |
| 12 | 2 | 40000.0 |
| 13 | 1 | 262.3 |
| 14 | 1 | 15000.0 |
| 15 | 1 | 9000.0 |
| 16 | 1 | 9000.0 |
| 17 | 8 | 43810.0 |
| 18 | 2 | 2080.2 |
| 19 | 1 | 5000.0 |
| 20 | | |
| 21 | 3 | 7745.7 |
| 22 | 7 | 80375.0 |
| 23 | 1 | 824.2 |
| 24 | 15 | 35685.8 |
| 25 | 6 | 5808.1 |
| 26 | 6 | 5808.1 |
| 27 | 4 | 1819.2 |
| 28 | 1 | 1000.0 |
| 29 | 2 | 5937.2 |
| 30 | 2 | 5937.2 |
| 31 | 1 | 15000.0 |
| 32 | 6 | 18757.8 |
| 33 | 1 | 853.0 |
| 34 | 1 | 10000.0 |
| 35 | 2 | 650.0 |
| 36 | 2 | 650.0 |
| 37 | 2 | 120.0 |
| 38 | 3 | 9914.0 |
| 39 | 6 | 250684.0 |
| 40 | 6 | 250684.0 |
| 41 | 1 | 262.3 |
| 42 | 55 | 972606.1 |
| 43 | 1 | 200.0 |
| 44 | 5 | 10786.9 |
| 45 | 1 | 500.0 |
| 46 | 1 | 500.0 |
| 47 | 1 | 262.3 |
| 48 | 1 | 1624.0 |
| 49 | 2 | 1351.0 |
| 50 | 2 | 1351.0 |
| 51 | 1 | 15000.0 |
| 52 | 1 | 57537.0 |
| 53 | 5 | 35143.0 |
| 54 | 2 | 6400.0 |
| 55 | 2 | 13000.0 |
| 56 | 2 | 13000.0 |
| 57 | 14 | 158595.7 |
| 58 | 5 | 7748.3 |
| 59 | 1 | 4000.0 |
| 60 | 1 | 150.0 |

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| 1 | | |
| 2 | 15 | 227311.4 |
| 3 | 2 | 11500.0 |
| 4 | 1 | 3000.0 |
| 5 | 1 | 4000.0 |
| 6 | 1 | 4000.0 |
| 7 | 5 | 15115.4 |
| 8 | 1 | 36000.0 |
| 9 | 1 | 2000.0 |
| 10 | 1 | 10000.0 |
| 11 | 1 | 10000.0 |
| 12 | 4 | 32597.2 |
| 13 | 11 | 38214.9 |
| 14 | 1 | 228.0 |
| 15 | 10 | 57018.2 |
| 16 | 10 | 57018.2 |
| 17 | 2 | 21101.4 |
| 18 | 14 | 98362.3 |
| 19 | 1 | 257.6 |
| 20 | 1 | 150.0 |
| 21 | 1 | 150.0 |
| 22 | 1 | 15000.0 |
| 23 | 3 | 7068.8 |
| 24 | 3 | 46207.0 |
| 25 | 2 | 15000.0 |
| 26 | 2 | 15000.0 |
| 27 | 8 | 87500.0 |
| 28 | 3 | 3900.0 |
| 29 | 3 | 1139.7 |
| 30 | 2 | 280.0 |
| 31 | 2 | 280.0 |
| 32 | 2 | 2355.5 |
| 33 | 1 | 603.4 |
| 34 | 1 | 6000.0 |
| 35 | 1 | 45.0 |
| 36 | 1 | 1000.0 |
| 37 | 1 | 1000.0 |
| 38 | 1 | 9600.0 |
| 39 | 1 | 300.0 |
| 40 | 4 | 48000.0 |
| 41 | 4 | 48000.0 |
| 42 | 13 | 118394.2 |
| 43 | 15 | 121433.8 |
| 44 | 2 | 1600.0 |
| 45 | 1 | 1500.0 |
| 46 | 1 | 3400.0 |
| 47 | 1 | 3400.0 |
| 48 | 1 | 15000.0 |
| 49 | 1 | 10000.0 |
| 50 | 1 | 10000.0 |
| 51 | 1 | 7405.6 |
| 52 | 1 | 1685.0 |
| 53 | 1 | 1250.0 |
| 54 | 4 | 1984.0 |
| 55 | 4 | 1984.0 |
| 56 | 11 | 83416.0 |
| 57 | 4 | 28328.7 |
| 58 | 1 | 400.0 |
| 59 | 1 | 8500.0 |
| 60 | 1 | 10000.0 |

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| 1 | | |
| 2 | 1 | 44000.0 |
| 3 | 2 | 412.3 |
| 4 | 1 | 5000.0 |
| 5 | 9 | 105050.0 |
| 6 | 1 | 4000.0 |
| 7 | 18 | 165556.8 |
| 8 | 9 | 178153.0 |
| 9 | 1 | 4500.0 |
| 10 | 1 | 20000.0 |
| 11 | 1 | 3000.0 |
| 12 | 1 | 981.0 |
| 13 | 1 | 2000.0 |
| 14 | 3 | 1139.3 |
| 15 | 1 | 30000.0 |
| 16 | 1 | 224.0 |
| 17 | 2 | 850.0 |
| 18 | 1 | 1000.0 |
| 19 | 1 | 1000.0 |
| 20 | 3 | 51000.0 |
| 21 | 2 | 2538.0 |
| 22 | 3 | 51568.0 |
| 23 | 1 | 5000.0 |
| 24 | 7 | 9052.8 |
| 25 | 1 | 23754.0 |
| 26 | 2 | 15000.0 |
| 27 | 3 | 9851.0 |
| 28 | 7 | 56002.3 |
| 29 | 2 | 262000.0 |
| 30 | 1 | 257.6 |
| 31 | 1 | 5000.0 |
| 32 | 3 | 91163.6 |
| 33 | 1 | 18000.0 |
| 34 | | |
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Web Supplement 15. Recipients - payments missing from patient organisation data (all years)**Patient organisation name**

21 and Co
AADC Research Trust
Action Bladder Cancer UK
Action Duchenne
Action on Pain
Action on Smoking and Health - Scotland
Actionplus Foundation
Addenbrooks Charitable Trust
African-Caribbean Leukaemia Trust
African's Getting Involved
Age Related Diseases and Health Trust
aHUS UK
ALD Life
Allergy Research Foundation
Alpha-1 Awareness UK
Alpha-1 UK Support Group
Alzheimer Scotland
Alzheimers Dementia Support
Angelman Syndrome Support Education Research Trust
Ankylosing Spondylitis International Federation
Anticoagulation UK
Aplastic Anaemia Trust
Arrhythmia Alliance
Arthritis and Musculoskeletal Alliance
Asthma and Allergy Foundation
Asthma Relief
Asyabi UK
Atrial Fibrillation Association
Back on Track
Barts and The London Charity
Basil Skyers Myeloma Foundation
Beat Parkinson's
Beating Bowel Cancer
Behcets Syndrome Society
Bipolar Scotland
Bipolar UK
Birdshot Uveitis Society
Bladder and Bowel Foundation (taken over by Bladder and Bowel Community in 2017)
Blood Pressure UK
Bluebell Foundation
Body and Soul
Bone Cancer Research Trust
Brain Charity
Brain Tumor Charity
Brain Tumour Research
Breast Cancer Campaign (current name Breast Cancer Now, following merger with Breakthrough Breast Canc

1
2 Breast Cancer Haven (The Haven)
3 British Dupuytren's Society
4 British Heart Foundation
5 British Obesity Society
6 British Polio Fellowship
7 British Skin Foundation
8 Brook
9
10 Building for the Future
11 Cambridge Rare Disease Network
12 Cancer 52
13 Cancer Focus Northern Ireland
14 Cancer Research UK
15 Candlelighters
16 Cardiac Risk in the Young
17 Cardiomyopathy UK
18 Catholics for AIDS Prevention and Support
19 Charlie Waller Memorial Trust
20 Children with Cancer UK
21 Children's Liver Disease Foundation
22 Children's Heart Unit Fund
23 Chinese National Healthy Living Centre
24 Chronic Lymphocytic Leukaemia Support Association
25 Cleft Lip and Palate Association
26 CLIC Sargent Cancer Care For Children
27 Community Cancer Centre
28 Contact a Family
29 Coping with Cancer in Leicestershire and Rutland
30 Crohn's in Childhood Research Association
31 Cure Parkinson's Trust
32 Cystic Fibrosis Trust
33 David Lewis Centre
34 Deaf Education through Listening and Talking
35 Delete Blood Cancer
36 Dementia UK
37 Diabetes Research and Wellness Foundation
38 Diabetics with Eating Disorders
39 Diamond Blackfan Anaemia UK
40 Different Strokes
41 Douglas Bader Foundation
42 Edinburgh and Lothian Prostate Cancer Support Group
43 Encephalitis Society
44 Epilepsy Connections
45 Epilepsy Scotland
46 FORCE
47 Forum Link
48 Freshwinds
49 Group B Strep Support UK
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Guillain Barre and associated inflammatory neuropathies

1 Haemophilia Society
2 Haemophilia Wales
3 Hafal
4 Headway
5 Health and Social Care Alliance Scotland
6 Heartbeat
7 Hepatitis B Positive Trust
8 HIV i-Base
9 Hughes Syndrome Foundation
10 ICUsteps
11 Imperial College Healthcare Charity
12 Independent Cancer Patients' Voice
13 Input Diabetes
14 KAITY
15 Karen Clifford Skcin cancer charity
16 Kidney Cancer Support Network
17 Kidney Cancer UK
18 Kidney Care UK
19 LATCH Welsh Children's Cancer Charity
20 Leeds Teaching Hospital Charitable Foundation
21 Leicestershire AIDS Support Services
22 Life Education Wessex
23 Little Hearts Matter
24 Liver4Life
25 Lullaby Trust
26 Lupus Europe
27 Lupus UK
28 Macular Society
29 Maggie's Centre
30 Make A Wish Foundation
31 Malnutrition and Nutritional Care in the UK
32 MAMA Academy
33 Marie Curie Cancer Care
34 Martin Fisher Foundation
35 Melanoma UK
36 Mesothelioma UK
37 Motor Neurone Disease Association
38 Movember Foundation
39 MPN Voice
40 Multi Organ Transplant Support
41 Multiple Births Foundation
42 Multiple Sclerosis UK
43 Myasthenia Gravis Association
44 Myrovlytis Trust
45 NARA - The Breathing Charity
46 National Association for Pre-Menstrual Syndrome
47 National Cancer Research Institute
48 National Eczema Society

1 National Kidney Federation
2 National Obesity Forum
3 National Osteoporosis Society
4 NMO Research Foundation
5 North of England Bone Marrow and Thalassaemia Association
6 Northern Ireland Chest, Heart and Stroke
7 Northern Ireland Rare Disease Partnership
8 OcuMel UK
9 Olive Tree Cancer Support Centre - Crawley
10 Oliver King Foundation
11 Orchid
12 Organisation for Sickle Cell Anaemia Research and Thalassaemia Support
13 Ovacome
14 Paget's Association
15 Pain Association Scotland
16 Pain Concern
17 Pain UK
18 Patients Association
19 Patients On Intravenous and Nasogastric Nutrition Therapy
20 Paula Carr Diabetes Trust
21 Pelican Cancer Foundation
22 Pelvic Pain Support Network
23 Pink Ribbon Foundation – Breast Cancer Charity
24 Polycystic Kidney Disease Charity
25 Portsmouth Down Syndrome Association
26 Positive Action
27 Prader-Willi Syndrome Association UK
28 Progressive Supranuclear Palsy Association
29 Prostate Cancer Research Centre
30 Prostate Cymru
31 QUIT
32 Rainbow Centre for Conductive Education
33 Rainbow Trust Children's Charity
34 Rarer Cancers Foundation
35 Restless Leg Syndrome UK
36 Richmond Fellowship
37 River House Trust
38 Ronald McDonald House Charities
39 Roy Castle Lung Cancer Foundation
40 Royal Marsden Cancer Charity
41 Salamander Trust
42 Samson Centre for MS
43 SANE
44 Scoliosis Association UK
45 Scotland Patients Association
46 Scottish Drugs Forum
47 Scottish Epilepsy Initiative
48 Scottish Kidney Federation

1
2 Scottish Network Children with Arthrities
3 SeeAbility
4 Self Help Services
5 Sense
6
7 Service by Emergency Response Volunteers - Suffolk and Cambridgeshire
8 Short Bowel Survivor and Friends
9 Silver Star
10 Skin Care Cymru
11 Somerville Foundation
12 Sophia Forum
13 Spectra
14 Spinal Injuries Association
15 Spinal Injuries Scotland
16 St Thomas Lupus Trust
17 Steps
18 SUDEP Action
19 Sussex Beacon
20 Tackle Prostate Cancer
21 Team Margot
22 Tenovus Cancer Care
23 Thames Valley Positive Support
24 Thrombosis UK
25 Transplant Links
26 Transverse Myelitis Society
27 Tree of Hope
28 Trigeminal Neuralgia Association
29 UK Chronic Lymphocytic Leukaemia Forum
30 UK Gout Society
31 UK Sepsis Trust
32 Walk the Walk Worldwide
33 Waverley Care
34 Willow Foundation
35 World Cancer Research Fund
36 World Child Cancer
37 York Air Ambulance
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Number of payments Value of payments (2016 £)

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| 1 | | |
| 2 | | |
| 3 | | |
| 4 | 1 | 1028.5 |
| 5 | 1 | 5070.3 |
| 6 | 1 | 101.0 |
| 7 | 1 | 101.0 |
| 8 | 12 | 47076.4 |
| 9 | 12 | 13947.1 |
| 10 | 1 | 2519.9 |
| 11 | 2 | 7940.8 |
| 12 | 2 | 7940.8 |
| 13 | 1 | 3042.2 |
| 14 | 6 | 70151.6 |
| 15 | 1 | 129.6 |
| 16 | 1 | 129.6 |
| 17 | 2 | 39258.9 |
| 18 | 1 | 25250.0 |
| 19 | 1 | 262.3 |
| 20 | 1 | 262.3 |
| 21 | 2 | 21041.7 |
| 22 | 2 | 16456.2 |
| 23 | 5 | 138585.3 |
| 24 | 2 | 563.6 |
| 25 | 1 | 1057.3 |
| 26 | 1 | 303.0 |
| 27 | 1 | 303.0 |
| 28 | 6 | 38722.8 |
| 29 | 76 | 375206.6 |
| 30 | 1 | 1616.0 |
| 31 | 1 | 1616.0 |
| 32 | 34 | 329518.1 |
| 33 | 32 | 262194.0 |
| 34 | 1 | 507.0 |
| 35 | 1 | 1014.1 |
| 36 | 1 | 1014.1 |
| 37 | 1 | 1500.0 |
| 38 | 104 | 621144.3 |
| 39 | 1 | 3809.2 |
| 40 | 1 | 205.7 |
| 41 | 1 | 205.7 |
| 42 | 4 | 35201.1 |
| 43 | 1 | 5050.0 |
| 44 | 42 | 342673.1 |
| 45 | 1 | 20281.1 |
| 46 | 1 | 20281.1 |
| 47 | 3 | 3193.8 |
| 48 | 3 | 4145.2 |
| 49 | 1 | 10000.0 |
| 50 | 1 | 10000.0 |
| 51 | 38 | 2271217.4 |
| 52 | 1 | 10520.8 |
| 53 | 2 | 776.4 |
| 54 | 6 | 97945.7 |
| 55 | 3 | 12160.6 |
| 56 | 3 | 12160.6 |
| 57 | 1 | 981.5 |
| 58 | 1 | 12675.7 |
| 59 | 1 | 262.3 |
| 60 | 7 | 81316.2 |

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| 1 | | |
| 2 | 5 | 47893.8 |
| 3 | 8 | 55592.3 |
| 4 | 7 | 1881.6 |
| 5 | 1 | 420.8 |
| 6 | 1 | 0.0 |
| 7 | 1 | 0.0 |
| 8 | 6 | 9784.6 |
| 9 | 12 | 95961.9 |
| 10 | 1 | 243.4 |
| 11 | 1 | 243.4 |
| 12 | 4 | 9320.3 |
| 13 | 26 | 249099.2 |
| 14 | 13 | 29164.3 |
| 15 | 57 | 1817634.9 |
| 16 | 57 | 1817634.9 |
| 17 | 1 | 0.0 |
| 18 | 7 | 6270.9 |
| 19 | 5 | 2338.0 |
| 20 | 1 | 4089.1 |
| 21 | 1 | 4089.1 |
| 22 | 1 | 1000.0 |
| 23 | 2 | 624.9 |
| 24 | 2 | 16010.0 |
| 25 | 1 | 736.5 |
| 26 | 1 | 736.5 |
| 27 | 1 | 252.5 |
| 28 | 12 | 86711.0 |
| 29 | 2 | 120.9 |
| 30 | 2 | 120.9 |
| 31 | 3 | 5412.1 |
| 32 | 1 | 1028.5 |
| 33 | 3 | 20369.3 |
| 34 | 1 | 4187.3 |
| 35 | 9 | 27581.2 |
| 36 | 9 | 27581.2 |
| 37 | 9 | 24748.9 |
| 38 | 17 | 281196.7 |
| 39 | 1 | 1892.5 |
| 40 | 1 | 526.0 |
| 41 | 1 | 526.0 |
| 42 | 3 | 14664.9 |
| 43 | 1 | 2592.9 |
| 44 | 3 | 6594.9 |
| 45 | 4 | 1547.3 |
| 46 | 4 | 1547.3 |
| 47 | 1 | 15150.0 |
| 48 | 5 | 10786.9 |
| 49 | 2 | 1384.1 |
| 50 | 2 | 1384.1 |
| 51 | 2 | 804.5 |
| 52 | 2 | 767.3 |
| 53 | 2 | 4085.1 |
| 54 | 7 | 6116.9 |
| 55 | 1 | 507.0 |
| 56 | 1 | 507.0 |
| 57 | 6 | 26164.4 |
| 58 | 2 | 11930.2 |
| 59 | 1 | 153.6 |
| 60 | 2 | 6400.0 |

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| 1 | | |
| 2 | 57 | 577521.6 |
| 3 | 10 | 13720.9 |
| 4 | 1 | 4000.0 |
| 5 | 1 | 150.0 |
| 6 | 1 | 37.6 |
| 7 | 1 | 757.5 |
| 8 | 1 | 5070.3 |
| 9 | 1 | 5070.3 |
| 10 | 13 | 63461.6 |
| 11 | 1 | 2104.2 |
| 12 | 1 | 2104.2 |
| 13 | 2 | 4156.5 |
| 14 | 1 | 4000.0 |
| 15 | 11 | 29891.2 |
| 16 | 1 | 30322.2 |
| 17 | 1 | 30322.2 |
| 18 | 1 | 2000.0 |
| 19 | 10 | 91665.0 |
| 20 | 9 | 101336.2 |
| 21 | 9 | 101336.2 |
| 22 | 37 | 183714.4 |
| 23 | 2 | 754.3 |
| 24 | 1 | 1010.0 |
| 25 | 1 | 353.5 |
| 26 | 1 | 353.5 |
| 27 | 4 | 22216.1 |
| 28 | 1 | 518.7 |
| 29 | 1 | 252.5 |
| 30 | 1 | 252.5 |
| 31 | 24 | 248299.0 |
| 32 | 1 | 0.0 |
| 33 | 4 | 55502.5 |
| 34 | 1 | 707.0 |
| 35 | 1 | 15.2 |
| 36 | 1 | 15.2 |
| 37 | 3 | 3412.9 |
| 38 | 2 | 764.6 |
| 39 | 1 | 883.8 |
| 40 | 1 | 202.0 |
| 41 | 1 | 202.0 |
| 42 | 3 | 643.0 |
| 43 | 1 | 15000.0 |
| 44 | 24 | 386833.4 |
| 45 | 7 | 34571.2 |
| 46 | 7 | 34571.2 |
| 47 | 2 | 280.0 |
| 48 | 1 | 1010.0 |
| 49 | 1 | 1010.0 |
| 50 | 6 | 44237.3 |
| 51 | 1 | 6084.3 |
| 52 | 1 | 505.0 |
| 53 | 1 | 603.4 |
| 54 | 1 | 2020.0 |
| 55 | 1 | 1420.3 |
| 56 | 1 | 1420.3 |
| 57 | 1 | 0.0 |
| 58 | 1 | 152.1 |
| 59 | 1 | 1000.0 |
| 60 | 14 | 23675.7 |

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| 1 | | |
| 2 | 30 | 396718.0 |
| 3 | 3 | 3508.5 |
| 4 | 35 | 326740.6 |
| 5 | 3 | 6650.0 |
| 6 | 4 | 5775.3 |
| 7 | 1 | 1028.5 |
| 8 | 2 | 4035.1 |
| 9 | 2 | 2080.6 |
| 10 | 1 | 3400.0 |
| 11 | 1 | 510.9 |
| 12 | 2 | 3334.2 |
| 13 | 2 | 4184.1 |
| 14 | 6 | 64181.1 |
| 15 | 3 | 24720.6 |
| 16 | 10 | 4636.2 |
| 17 | 11 | 16888.4 |
| 18 | 10 | 30100.6 |
| 19 | 48 | 345520.4 |
| 20 | 5 | 29848.9 |
| 21 | 1 | 400.0 |
| 22 | 1 | 8500.0 |
| 23 | 4 | 2654.7 |
| 24 | 1 | 10000.0 |
| 25 | 4 | 68956.0 |
| 26 | 1 | 151.5 |
| 27 | 1 | 0.0 |
| 28 | 1 | 473.4 |
| 29 | 3 | 563.8 |
| 30 | 1 | 1052.1 |
| 31 | 1 | 639.6 |
| 32 | 13 | 79339.8 |
| 33 | 1 | 579.3 |
| 34 | 1 | 1010.0 |
| 35 | 62 | 682970.9 |
| 36 | 5 | 12939.6 |
| 37 | 1 | 736.5 |
| 38 | 1 | 252.5 |
| 39 | 1 | 771.4 |
| 40 | 70 | 770325.1 |
| 41 | 1 | 354.9 |
| 42 | 2 | 720.7 |
| 43 | 1 | 4500.0 |
| 44 | 7 | 83686.8 |
| 45 | 1 | 277.7 |
| 46 | 1 | 1028.5 |
| 47 | 2 | 4056.2 |
| 48 | 2 | 78625.5 |
| 49 | 1 | 505.0 |

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|----|----|----------|
| 1 | | |
| 2 | 3 | 1139.3 |
| 3 | 1 | 473.4 |
| 4 | 2 | 514.3 |
| 5 | 1 | 151.5 |
| 6 | 1 | 210.4 |
| 7 | 1 | 224.0 |
| 8 | 1 | 224.0 |
| 9 | 12 | 117958.9 |
| 10 | 8 | 19924.8 |
| 11 | 3 | 7327.7 |
| 12 | 2 | 10120.3 |
| 13 | 1 | 1010.0 |
| 14 | 1 | 252.5 |
| 15 | 1 | 1052.1 |
| 16 | 4 | 62950.0 |
| 17 | 1 | 151.5 |
| 18 | 2 | 2334.0 |
| 19 | 1 | 1000.0 |
| 20 | 13 | 148469.6 |
| 21 | 1 | 5050.0 |
| 22 | 9 | 170502.5 |
| 23 | 2 | 5736.5 |
| 24 | 17 | 45782.5 |
| 25 | 2 | 1531.9 |
| 26 | 1 | 15150.0 |
| 27 | 1 | 151.5 |
| 28 | 3 | 4208.3 |
| 29 | 1 | 4056.2 |
| 30 | 3 | 38407.4 |
| 31 | 1 | 0.0 |
| 32 | 1 | 405.6 |
| 33 | 18 | 103557.2 |
| 34 | 1 | 257.6 |
| 35 | 1 | 5000.0 |
| 36 | 15 | 342275.9 |
| 37 | 1 | 0.0 |
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Web Supplement 16. Shared ties in industry and patient organisation data based on the number and value**Ties calculated based on the number of payments**

Total number of ties reported in industry data involving at least one payment

Total number of ties reported in patient organisation data involving at least one payment

Number of shared ties (donors and recipients are the same in industry and patient organisation data)

Shared ties as a share of all ties in industry data

Shared ties as a share of all ties in patient organisation data

Number of ties involving the same number of payments

Number of ties involving the same number of payments as a share of shared ties

Number of payments forming ties with the equal number of payments in both datasets

Payments forming ties with the equal number of payments in both datasets as a share of all payments in industry data

Payments forming ties with the equal number of payments in both datasets as a share of all payments in patient organisation data

Ties calculated based on the value of payments

Total number of ties reported in industry data involving at least one payment with value >£0

Total number of ties reported in patient data involving at least one payment with value >£0

Number of shared ties (donors and recipients are the same in industry and patient organisation data)

Shared ties as a share of all ties in industry data

Shared ties as a share of all ties in patient organisation data

Number of shared ties involving the same value of payments

Shared ties involving the same value of payments as a share of shared ties

Value of payments in which donors and recipients provided the same value (2016 £)

Value of shared payments as a share of payments with values >£0 in industry data

Value of shared payments as a share of payments with values >£0 in patient organisation data

| | All years | 2012 | 2013 | 2014 | 2015 | 2016 |
|----|------------------|-------------|-------------|-------------|-------------|-------------|
| 1 | | | | | | |
| 2 | | | | | | |
| 3 | | | | | | |
| 4 | | | | | | |
| 5 | 1101 | 369 | 366 | 432 | 479 | 523 |
| 6 | 626 | 252 | 276 | 293 | 319 | 287 |
| 7 | | | | | | |
| 8 | | | | | | |
| 9 | 428 | 110 | 122 | 146 | 168 | 160 |
| 10 | 38.9% | 29.8% | 33.3% | 33.8% | 35.1% | 30.6% |
| 11 | 68.4% | 43.7% | 44.2% | 49.8% | 52.7% | 55.7% |
| 12 | | | | | | |
| 13 | | | | | | |
| 14 | 87 | 45 | 66 | 69 | 89 | 64 |
| 15 | 20.3% | 40.9% | 54.1% | 47.3% | 53.0% | 40.0% |
| 16 | | | | | | |
| 17 | | | | | | |
| 18 | 162 | 47 | 69 | 79 | 97 | 73 |
| 19 | 3.8% | 6.1% | 9.8% | 9.6% | 10.4% | 6.7% |
| 20 | 9.8% | 16.2% | 21.2% | 22.8% | 26.9% | 21.7% |
| 21 | | | | | | |
| 22 | | | | | | |
| 23 | | | | | | |
| 24 | | | | | | |
| 25 | 1088 | 366 | 357 | 431 | 470 | 522 |
| 26 | 326 | 127 | 122 | 119 | 150 | 140 |
| 27 | | | | | | |
| 28 | | | | | | |
| 29 | 34 | 21 | 24 | 28 | 32 | 24 |
| 30 | 3.1% | 5.7% | 6.7% | 6.5% | 6.8% | 4.6% |
| 31 | 10.4% | 16.5% | 19.7% | 23.5% | 21.3% | 17.1% |
| 32 | | | | | | |
| 33 | | | | | | |
| 34 | 20 | 17 | 22 | 26 | 30 | 23 |
| 35 | 58.8% | 81.0% | 91.7% | 92.9% | 93.8% | 95.8% |
| 36 | | | | | | |
| 37 | | | | | | |
| 38 | 325,108.4 | 216,055.8 | 201,362.3 | 251,964.6 | 517,139.2 | 482,216.0 |
| 39 | 0.6% | 2.8% | 3.3% | 2.9% | 4.5% | 2.4% |
| 40 | 1.0% | 6.2% | 4.6% | 4.8% | 10.7% | 3.2% |
| 41 | | | | | | |
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Web Supplement 17. Overlap between recipient lists reported by donors and patient organ

| | Total number of donors with at least one payment | Minimum overlap with patient organisation data | Number of donors with minimum overlap with patient organisation data | Donors with minimum overlap with patient organisation data as a share of all donors | Number of donors with less than 50% overlap with patient organisation data | Donors with less than 50% overlap with patient organisation data as a share of all donors |
|-----------|--|--|--|---|--|---|
| All years | 63 | 0.0% | 6 | 9.5% | 40 | 63.5% |
| 2012 | 30 | 0.0% | 7 | 23.3% | 23 | 76.7% |
| 2013 | 38 | 0.0% | 9 | 23.7% | 25 | 65.8% |
| 2014 | 45 | 0.0% | 12 | 26.7% | 35 | 77.8% |
| 2015 | 51 | 0.0% | 11 | 21.6% | 33 | 64.7% |
| 2016 | 44 | 0.0% | 10 | 22.7% | 32 | 72.7% |

isation data - yearly breakdown based on the number of payment

| Maximum overlap with patient organisation data | Number of donors with maximum overlap with patient organisation data | Donors with maximum overlap with patient organisation data as a share of all donors |
|--|--|---|
| 100.0% | 3 | 4.8% |
| 100.0% | 1 | 3.3% |
| 100.0% | 4 | 10.5% |
| 100.0% | 3 | 6.7% |
| 100.0% | 3 | 5.9% |
| 100.0% | 3 | 6.8% |

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Web Supplement 18. Overlap between recipient lists reported by donors and patient organ

| | Number of donors with at least one payment with the value >£0 | Minimum overlap with patient organisation data | Number of donors with minimum overlap with patient organisation data | Donors with minimum overlap with patient organisation data as a share of all donors | Number of donors with 50% overlap with patient organisation data | Donors with less than 50% overlap with patient organisation data as a share of all donors |
|-----------|---|--|--|---|--|---|
| All years | 62 | 0.0% | 17 | 27.4% | 56 | 90.3% |
| 2012 | 30 | 0.0% | 13 | 43.3% | 29 | 96.7% |
| 2013 | 38 | 0.0% | 18 | 47.4% | 36 | 94.7% |
| 2014 | 45 | 0.0% | 26 | 57.8% | 45 | 100.0% |
| 2015 | 50 | 0.0% | 21 | 42.0% | 42 | 84.0% |
| 2016 | 44 | 0.0% | 15 | 34.1% | 39 | 88.6% |

isation data - yearly breakdown based on the value of payments

| Maximum overlap with patient organisatio n data | Number of donors with maximum overlap with patient organisatio n data | Donors with maximum overlap with patient organisatio n data as a share of all donors |
|---|---|--|
| 100.0% | 2 | 3.2% |
| 50.0% | 1 | 3.3% |
| 66.7% | 1 | 2.6% |
| 40.0% | 1 | 2.2% |
| 100.0% | 1 | 2.0% |
| 66.7% | 1 | 2.3% |

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Web Supplement 19. Overlap between donor lists reported by recipients and industry data

| | Number of recipients with at least 1 payment | Minimum overlap with industry data | Number of recipients with minimum overlap with industry data | Recipients with minimum overlap with industry data as a share of all recipients | Number of recipients with less than 50% overlap with industry data | Recipients with less than 50% overlap with industry data as a share of all recipients |
|-----------|--|------------------------------------|--|---|--|---|
| All years | 200 | 0.0% | 14 | 7.0% | 32 | 16.0% |
| 2012 | 103 | 0.0% | 37 | 35.9% | 51 | 49.5% |
| 2013 | 102 | 0.0% | 38 | 37.3% | 50 | 49.0% |
| 2014 | 116 | 0.0% | 34 | 29.3% | 49 | 42.2% |
| 2015 | 126 | 0.0% | 37 | 29.4% | 47 | 37.3% |
| 2016 | 117 | 0.0% | 28 | 23.9% | 40 | 34.2% |

- yearly breakdown based on the number of payments

| | Number of recipients with maximum overlap with industry data | Maximum overlap with industry data | Receipts with maximum overlap with industry data as a share of all recipients |
|--|--|------------------------------------|---|
| | 102 | 100.0% | 51.0% |
| | 29 | 100.0% | 28.2% |
| | 24 | 100.0% | 23.5% |
| | 41 | 100.0% | 35.3% |
| | 49 | 100.0% | 38.9% |
| | 50 | 100.0% | 42.7% |

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Web Supplement 20. Overlap between donor lists reported by recipients and industry data -

| | Number of patient organisations with at least one payment with the value >0 | Minimum overlap with industry data | Number of recipients with minimum overlap with industry data | Recipients with minimum overlap with industry data as a share of all recipients | Number of recipients with less than 50% overlap with industry data | Recipients with less than 50% overlap with industry data as a share of all recipients |
|-----------|---|------------------------------------|--|---|--|---|
| All years | 121 | 0.0% | 12 | 9.9% | 18 | 14.9% |
| 2012 | 57 | 0.0% | 22 | 38.6% | 30 | 52.6% |
| 2013 | 51 | 0.0% | 19 | 37.3% | 26 | 51.0% |
| 2014 | 58 | 0.0% | 17 | 29.3% | 21 | 36.2% |
| 2015 | 72 | 0.0% | 22 | 30.6% | 26 | 36.1% |
| 2016 | 57 | 0.0% | 10 | 17.5% | 15 | 26.3% |

- yearly breakdown based on the value of payments

| | Number of recipients with maximum overlap with industry data | Receipts with maximum overlap with industry data as a share of all recipients |
|------------------------------------|--|---|
| Maximum overlap with industry data | 71 | 58.7% |
| 100.0% | 16 | 28.1% |
| 100.0% | 14 | 27.5% |
| 100.0% | 27 | 46.6% |
| 100.0% | 35 | 48.6% |
| 100.0% | 31 | 54.4% |

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STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

| | Item No | Recommendation | Page No |
|------------------------------|---------|---|------------------------|
| Title and abstract | 1 | (a) Indicate the study's design with a commonly used term in the title or the abstract | 4 |
| | | (b) Provide in the abstract an informative and balanced summary of what was done and what was found | 4 |
| Introduction | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 5 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | 5 |
| Methods | | | |
| Study design | 4 | Present key elements of study design early in the paper | 6 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 6 |
| Participants | 6 | (a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up | 6 |
| | | (b) For matched studies, give matching criteria and number of exposed and unexposed | N/A |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 7 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | 7 |
| Bias | 9 | Describe any efforts to address potential sources of bias | 6 |
| Study size | 10 | Explain how the study size was arrived at | 6 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | 7 |
| Statistical methods | 12 | (a) Describe all statistical methods, including those used to control for confounding | 7 |
| | | (b) Describe any methods used to examine subgroups and interactions | N/A |
| | | (c) Explain how missing data were addressed | 6 |
| | | (d) If applicable, explain how loss to follow-up was addressed | N/A |
| | | (e) Describe any sensitivity analyses | N/A |
| Results | | | |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 7 |
| | | (b) Give reasons for non-participation at each stage | N/A |
| | | (c) Consider use of a flow diagram | Web supplement 1 and 2 |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | 7-8 |
| | | (b) Indicate number of participants with missing data for each variable of interest | 6,16 |
| | | (c) Summarise follow-up time (eg, average and total amount) | Table 1 |
| Outcome data | 15* | Report numbers of outcome events or summary measures over time | 7-20 |

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|----|--------------------------|----|--|-------|
| 1 | Main results | 16 | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 7-20 |
| 2 | | | (b) Report category boundaries when continuous variables were categorized | 10-15 |
| 3 | | | (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | N/A |
| 4 | | | | |
| 5 | Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | N/A |
| 6 | | | | |
| 7 | Discussion | | | |
| 8 | Key results | 18 | Summarise key results with reference to study objectives | 20-22 |
| 9 | Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 22-23 |
| 10 | Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 23 |
| 11 | Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 22 |
| 12 | Other information | | | |
| 13 | Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 2 |
| 14 | | | | |

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.