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A 'patient–industry complex'? Investigating the financial dependency of UK patient organisations on drug company funding

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Abstract

We examined the minimum extent of dependency of UK patient organisations on pharmaceutical industry funding using drug company disclosure reports and patient organisation financial accounts from 2012 to 2016. We used linear regression to explain the overall share of industry funding ('general dependency') and top donor funding ('company-specific dependency') in organisations' income. Predictors included patient organisations' goal; having members and volunteers; geographical scope of activity; headquarter location; expenditure/income ratio; and disease area. The prevalent low levels of general dependency (IQR, 0.1%–6.0%) and company-specific dependency (IQR, 0.1%–4.3%) made a widespread capture of patient organisations unlikely, though only if one excludes the possibility of significant payment under-reporting. However, organisations with considerably higher dependency than others might be more prone to co-optation by industry. Of the 398 organisations, 18 (4.5%) and 8 (2.0%) had general and company-specific financial dependency over 50%, respectively. However, the shares of outliers exceeding the third quartile plus 1.5 times IQR were 51 (12.8%) and 56 (14.1%) for each dependency type. Certain

characteristics including activity profile (advocacy) or indicating limited access to resources (remote location) made organisations vulnerable to developing financial dependency. Future research should examine both financial and non-financial links between the two sides and their impact on patient organisations' activity.

KEYWORDS

conflicts of interest, financial dependency, patient organisations, pharmaceutical industry, transparency

INTRODUCTION

Patient organisations increasingly shape healthcare research, delivery and policy but their growing influence is matched by concerns about widespread collaboration with drug companies (Baggott et al., 2005; Batt, 2017; Wood, 2000).

The first social scientific perspective on the relationships between the industry and patient organisations is offered within the 'neoliberal corporate bias' theory of pharmaceutical regulation, developed mainly with UK, EU-level and US material (Abraham, 1995, 2009; Abraham & Lewis, 2000; Davis & Abraham, 2013; House of Commons Health Committee, 2005, pp. 74–77). It sees consumerism—'the ideology and movement regarding patients as "consumers" in a marketplace'—as a hallmark of the neoliberal era of pharmaceutical regulation starting from the 1980s (Abraham, 2009, pp. 962–967; Abraham, 2010, pp. 612–613; Davis & Abraham, 2013, pp. 103–104). The consumerist ideology has been driven by deregulatory reforms, advocated by the industry and sympathetic policymakers, and by patient activism, which companies seek to use as a way of increasing demand and product sales (Davis & Abraham, 2013, pp. 104–106). One form of alliance between manufacturers and 'access-oriented (patient) consumerism' (Abraham, 2010, pp. 611–613) has been the 'patient–industry complex', detected using case studies of medicines in commercially high-profile areas including cancer (Abraham, 2009; Davis & Abraham, 2013). It takes the form of 'extensive collaborations' with patient organisations playing vital roles in industry-orchestrated marketing, lobbying and litigation campaigns (Abraham, 2009, pp. 956–957, 963–967; Davis & Abraham, 2013, pp. 106–107, 197). Patient organisations acting as industry's 'assimilated allies' may facilitate regulatory decisions favourable to the industry (Abraham, 2009, pp. 963–967; Davis & Abraham, 2013, pp. 113, 226), while sometimes contradicting patients' interests in accessing safe and effective drugs (Davis & Abraham, 2013, pp. 170–172, 179).

The alternative perspective is disease–politics theory (Carpenter, 2010; Daemmrich, 2004). While examining a similar period in US drug regulation as Davis and Abraham (2013), it shows less interest in the deregulatory context of neoliberalism (Carpenter, 2010, pp. 395, 429; Daemmrich, 2004, pp. 32–34). It emphasises, instead, the emergence of disease as the category organising constituencies in the medical field which often engage in political struggles over the characteristics of illness and medicines (Carpenter, 2010, pp. 396–397; Daemmrich, 2004, pp. 4–5). Consequently, disease–politics scholars examine condition-based patient organisations in policy debates surrounding drug approvals, primarily for AIDS and cancer (Carpenter, 2010; Daemmrich, 2004).

Like in the patient–industry complex position, patient organisations display consumerist orientations, but they represent patient reflexivity and expertise (Daemmrich, 2004, pp. 32–33) or express 'political organization and representation' (Carpenter, 2010, p. 42). In seeking wider, expedited access to therapies seen as promising, they employ symbolic and institutional resources. The former comprise group identity, legitimacy or credibility, and lived patient experience (Carpenter, 2010, pp. 399, 430–432, 445; Daemmrich, 2004, pp. 11–12, 31, 107), while the latter—well-developed organisational structures and mobilised activists (Carpenter, 2010, p. 399; Daemmrich, 2004, pp. 30–31, 43). These resources are generated through networks involving other policy actors, including regulators and policymakers (Carpenter, 2010, pp. 398, 430–431; Daemmrich, 2004, pp. 11–12, 99–100).

Unlike in neoliberal corporate bias theory, here patient organisations are not seen as 'influence of the industry by proxy' (Davis & Abraham, 2013, pp. 233–234) but as more autonomous or even driving advocacy coalitions (Carpenter, 2010, pp. 430–431, 445; Daemmrich, 2004, pp. 99–101). Both accounts agree that patient organisations can wield decisive policy influence (Carpenter, 2010, pp. 10, 445; Daemmrich, 2004, p. 14) but in the 'patient–industry' complex position success typically depends on industry support (Abraham, 2010, p. 612). However, disease–politics scholars either do not examine the consistency between regulatory outcomes and patients' interests (Carpenter, 2010) or see these interests as socially constructed and subject to evolving interpretations (Daemmrich, 2004, p. 27; cf. Davis & Abraham, 2013, pp. 13–14).

Industry–patient organisation relationships and financial dependency

The patient–industry complex involves multiple 'organisational links' with drug companies (Davis & Abraham, 2013, p. 107) established directly or mediated by public relations firms (Batt, 2017, pp. 187–189; Herxheimer, 2003; O'Donovan, 2007) or non-profit entities (McCoy et al., 2017). Key examples include provision of expertise, training, logistical support or partnership activities, such as 'patient access programmes' to new medicines (Davis & Abraham, 2013, p. 167; Herxheimer, 2003; House of Commons Health Committee, 2005, p. 75; Ozieranski & King, 2017, pp. 593–596; Parker et al., 2019). However, the most tangible, and perhaps most often highlighted dimension, is funding and the associated problem of financial dependency on drug companies (Baggott et al., 2005, pp. 191–195; Davis & Abraham, 2013, pp. 106–107, 167–168, 215; Jones, 2008; O'Donovan, 2007; Parker et al., 2019).

Financial dependency often arises from funding requests made by patient organisations engaging in increasingly diverse activities while having access to few alternatives, such as public grants (Baggott & Jones, 2015, pp. 192–195; Ball et al., 2006; Batt, 2017, pp. 141, 169–170; House of Commons Health Committee, 2005, p. 75; O'Donovan, 2007; Ozieranski & King, 2017, p. 594; Parker et al., 2019). Financial dependency can also result from consumerist ideology encouraging patient organisations to collaborate with the industry when 'tactically advantageous' (Abraham, 2009, p. 964; Jones, 2008, p. 935) or drug companies being perceived as legitimate and desirable allies (O'Donovan, 2007; Parker et al., 2019). Correspondingly, organisations with profiles closely aligned with industry interests are more likely to secure funding (Batt, 2017, pp. 188–192). Conversely, financial dependency can follow from company overtures, such as provision of 'foundational funding' for organisations representing conditions relevant for newly marketed products (Batt, 2017, pp. 104–109; Ozieranski & King, 2017, p. 594; Parker et al., 2019).

The impact of financial dependency is often 'difficult to gauge' (Davis & Abraham, 2013, p. 106), not least because even extensively sponsored organisations may support some industry

agendas while undermining others (O'Donovan, 2007). Nevertheless, financial dependency may shape organisations' 'cultures of action'—'the meanings, values, tacit knowledge, and modes of behaviour that organisations manifest', resulting in their 'corporate colonisation' (O'Donovan, 2007, p. 715). Specifically, it may prompt some to promote products lacking appropriate scientific evidence (Baggott et al., 2005, pp. 197–199; House of Commons Health Committee, 2005, pp. 75–76; Jones, 2008, pp. 938–939; Wood, 2000, p. 83). Further, it may shape organisational agendas and ideologies (Batt, 2017, pp. 271–272; Davis & Abraham, 2013, pp. 965–967; O'Donovan, 2007) and ultimately undermine organisations' representativeness and credibility (Ball et al., 2006; Batt, 2017, p. 288; Herxheimer, 2003; Jones, 2008, p. 938).

Research typically emphasises risks associated with 'substantial' financial dependency, without specifying thresholds (Baggott et al., 2005, p. 193; Batt, 2017, p. 136; Davis & Abraham, 2013, pp. 106, 215; House of Commons Health Committee, 2005, p. 75; Jones, 2008, p. 934). Some organisations dispute this, highlighting the lack of donors' attempts to influence their activity (Batt, 2017, pp. 121–122; Jones, 2008, p. 936), or such influence having no effect (Arie & Mahony, 2014; Batt, 2017, pp. 177–178). Others, however, only accept limited or no industry income (Arie & Mahony, 2014; Baggott et al., 2005, p. 193; Batt, 2017, pp. 138–140, 164–168; Jones, 2008, p. 932).

We use the concept of financial dependency to ascertain whether the patient–industry complex or disease–politics position better explains pharmaceutical industry–patient organisation relationships in the UK. Each account would expect a different overall extent of financial dependency of patient organisations on industry funding—*higher* (patient–industry complex position) or *lower* (disease–politics position). They would also expect varying financial dependency levels across patient organisations with characteristics highlighted by their respective theoretical foci. The patient–industry complex thesis would expect *higher* dependency in organisations representing commercially high-profile disease areas and those undertaking activities potentially complementing company lobbying and marketing strategies. Conversely, disease–politics theory would expect *lower* dependency in organisations commanding symbolic and organisational resources potentially reducing the need for industry funding.

Operationalising financial dependency

We distinguish *general* and *company-specific* financial dependency. The former is the share of industry funding in an organisation's income. It has been investigated primarily in the United States, with Rose et al. (2017) highlighting that of 160 patient organisations with corporate funding 19 (11.9%) received over 50% of their income from pharmaceutical, device and biotechnology companies. Others, however, have identified lower revenue shares (McCoy et al., 2017). *General dependency* has been rarely studied in Europe, except for a Finnish study noting that 4 of 39 (10.3%) organisations reporting pharmaceutical industry funding had over 20% of their annual income from this source (Hemminki et al., 2010).

By contrast, *company-specific dependency* is the top drug company donor's share in an organisation's income. This concept recognises that receiving substantial contributions from many donors (high *general dependency*) may still allow some autonomy given their potentially conflicting interests. Conversely, receiving funding from one or few companies is particularly detrimental (Jones, 2008, p. 937). Acknowledging the risks associated with monopolistic relationships, the Association of the British Pharmaceutical Industry (ABPI, 2019, p. 39) recommends that companies following its Code should not demand to be 'the sole funder of a patient organisation or any of its programmes'. *Company-specific dependency* has not been examined systematically, with the

only available UK data showing that for 81% of organisations (no totals) funded by three companies, the share of funding from those companies was lower than 10% (Jones, 2008).

One important caveat in interpreting the analyses of financial dependency is their reliance on patient organisations' self-reporting—mandatory, using, for example, tax records (McCoy et al., 2017)—and voluntary, including websites (Jones, 2008; McCoy et al., 2017) or surveys (Hemminki et al., 2010; Rose et al., 2017). Given the evidence of under-reporting of industry funding by patient organisations in both mandatory (Mandeville et al., 2019) and voluntary disclosures (Colombo et al., 2012; Ozieranski et al., 2020), these findings most likely reflect a *minimum* level of dependency.

Research questions and hypotheses

We examine the expectations from the patient–industry complex and disease–politics positions by exploring to what extent UK patient organisations are dependent on funding from the industry and specific companies; and what makes some more financially dependent than others.

We have two hypotheses regarding the extent of financial dependency:

- Consistent with existing European research (Hemminki et al., 2010), we expect low average levels of *general dependency*, with few exceptional cases of high dependency (**hypothesis 1**).
- Following the UK research on funding involving few industry donors (Jones, 2008), we expect low average levels of *company-specific dependency* (and necessarily not higher than *general dependency*), with few exceptional cases of high dependency (**hypothesis 2**).

Without a conventional understanding of 'high dependency', we use two cut-off points. First, following the statistical definition of outliers, we consider cases of *general* or *company-specific dependency* as exceptional if they exceed 1.5 times the interquartile range (IQR) above the third quartile. Second, exceptional cases have over 50% of their funding coming from the industry (*general dependency*) or the top donor (*company-specific dependency*). For both **hypotheses 1 and 2,** we expect the share of exceptional cases to be lower than 10% of the overall number of organisations.

As we sought to investigate a large sample of organisations using online research, we could not explore systematically their symbolic resources suggested by disease–politics theory. Instead, we examined their institutional resources also highlighted in existing UK research. Specifically, we explored the following characteristics which could be associated with either higher or lower shares of industry funding in organisational income:

- **Organisational goal**: UK patient organisations report having many goals (Baggott et al., 2005, pp. 89–95; Wood, 2000, pp. 57–60), with the fundamental distinction being between single-purpose organisations, for example, focussing on patient support or advocacy, and those combining different goals (Ozieranski et al., 2019). We expect that multipurpose organisations will require more resources to undertake their activities. Given the increasing difficulties in accessing alternatives to industry funding (Baggott & Jones, 2015), they may become more financially dependent (**hypothesis 3**).
- **Members and volunteers**: The reported prevalence of membership in UK patient organisations varies depending on the sample (Baggott et al., 2005, pp. 103–104; Wood, 2000, pp. 51, 61). Key resources associated with membership include financial contributions and networking

(Baggott et al., 2005, pp. 99, 104). The prevalence of volunteers is unequivocal as nearly a quarter of organisations use them exclusively to operate (Baggott et al., 2005, p. 97; Wood, 2000, pp. 17, 61). We expect organisations with members (**hypothesis 4**) and volunteers (**hypothesis 5**) to have access to alternative resources reducing the need for industry funding and therefore financial dependency.

- **Geographical scope of activity:** UK patient organisations' scope of activity varies from local to international, but only national-level organisations have been examined (Baggott et al., 2005, p. 20; Wood, 2000, p. 9). We expect organisations with an international scope to have the most comprehensive activities and therefore need more resources than those with a narrower scope. These organisations will also have extensive possibilities for engaging with multinational drug companies and scarce funding alternatives (Baggott & Jones, 2015). Therefore, they will more be financially dependent (**hypothesis 6**).
- **Headquarter location**: Almost 40% of patient organisations from a UK national sample were headquartered in London (Baggott et al., 2005, p. 38). However, little is known about how location may affect differences in organisational resources. As England's economic performance has recently outpaced other parts of the UK (Office for National Statistics, 2019b), we expect organisations headquartered outside England to have access to fewer resources and therefore be more dependent on industry funding (**hypothesis 7**). Additionally, the capital city in England, Scotland, Wales and Northern Ireland has generally performed better economically than the country as a whole (Office for National Statistics, 2019b). Therefore, we expect more financial dependency in organisations located further away from the country capitals as they have access to fewer resources (**hypothesis 8**).
- **Expenditure/income ratio:** UK patient organisations have widely varying incomes and expenditures (Baggott et al., 2005, pp. 95–97; Wood, 2000, p. 62), with the key concern being the ability to balance the books (Baggott et al., 2005, p. 102; Wood, 2000, p. 72). Consequently, we expect that organisations with higher ratios of expenditure to income require more industry funding and therefore are more financially dependent (**hypothesis 9**).
- **Disease area**: Levels of industry funding vary greatly across organisations representing different condition areas (Ozieranski et al., 2019). These differences often reflect company product portfolios and the number of new launches (Baggott et al., 2005, p. 187; Mulinari, Vilhelmsson, et al., 2020). We expect that we can identify disease areas in which organisations have higher dependency levels compared with organisations outside of a given area (**hypothesis 10**).

METHODS

Database development and integration

Drug company payments and patient organisation incomes

In the UK, patient organisations and drug companies declare funding voluntarily but companies choosing to follow the ABPI Code (ABPI, 2019) are required by the Code to do so (Clause 27.7). Both sides have been found to underreport funding made or received (Ozieranski et al., 2020; Rickard et al., 2019). However, the sums underreported by industry have been, on balance, smaller (Ozieranski et al., 2020), probably reflecting a single approach to disclosure (ABPI, 2019), contrasted with disparate ethical codes adopted by some patient organisations without central standards or oversight (Jones, 2008; Rickard et al., 2019). Failure to disclose by companies may

also involve sanctions by the ABPI's self-regulatory body (Mulinari et al., 2020). Therefore, we chose drug company reporting to calculate the amount of funding received, although it only represents a *minimum* level of financial dependency.

Our company sample comprised all 108 participants of Disclosure UK in 2015 (Appendix_1-2 in Ozieranski et al., 2021; available under the following web link: https://doi.org/10.15125/BATH-00904), an industry-run platform for the disclosure of payments to healthcare professionals and organisations (ABPI, 2020). We chose Disclosure UK as its participants, including 53 ABPI members, subscribe to the ABPI Code and therefore are also expected to disclose direct and indirect payments to patient organisations annually on their websites. Importantly, while no precise estimate of the total number of companies is available, 'virtually all pharmaceutical companies operating in the UK' (ABPI, 2019, p. 6) follow the ABPI Code.

An alternative sampling strategy, starting with patient organisations (Baggott et al., 2005; Wood, 2000), might have identified organisations without industry funding, including those which refused it. Nevertheless, their share would likely be small as a previous UK study found that only two of thirty-four organisations rejected it on principle (Jones, 2008, p. 932). The alternative sampling strategy might have also revealed funding from companies not following the ABPI Code, without any disclosure obligations (Ozieranski et al., 2020). However, their share would likely be minimal given the Disclosure UK's extensive coverage.

Overall, we identified 220 payment disclosure reports published by 66 of the 108 (61.1%) Disclosure UK participants between 2012 and 2016 (Appendix_1: https://doi.org/10.15125/BATH-00904). ER collected the data twice, in June 2017 and January 2018, to ensure that no available reports were missed. It remains unclear whether the 42 (38.9%) non-disclosing companies failed their obligations to disclose, removed published reports prematurely or had no payments to disclose. These companies were generally smaller—just 3 (7.1%) appeared on the global top 50 list and none were among the top 40, whereas 35 (53.0%) of the included (disclosing) companies appeared in the rankings (PharmExec.com, 2016).

After excluding ineligible recipients (Appendix_1: https://doi.org/10.15125/BATH-00904), we identified 489 organisations to which 64 (97.0%) companies made 4,572 payments, worth £57,305,289.2, following conversion to 2016 GBP using the Consumer Price Index data (Office for National Statistics, 2019a). This is unlikely to be a complete payment list as some companies have underreported, as demonstrated by the partial data from recipients (Ozieranski et al., 2020). Of the collected payments, 425 (86.9%) organisations, receiving 4,316 (94.4%) payments, worth £54,071,454.2 (94.4%), from 63 (98.4%) companies were registered as charities with at least one UK charity regulator, namely the Charity Commission for England and Wales, the Scottish Charity Regulator or the Charity Commission for Northern Ireland. The exclusion of non-charity patient organisations was necessary as they do not have to publish income and expenditure information. However, their exclusion should not influence the results as they formed a small share of the initial sample of organisations receiving industry funding. After excluding payments with values of zero (primarily 'benefits in kind' without monetary equivalents), the industry data set comprised 4,235 (98.1%) payments from 62 (98.4%) companies to 416 (97.9%) patient organisations.

We also used the charity regulators' websites to collect the annual accounts of patient organisations mentioned in drug company disclosure reports. For all organisations included in the analysis, ER downloaded 1,382 yearly financial accounts, including details of income and expenditure, in September 2017 and then July 2018. We considered financial years starting from 2011/2012 and ending in 2016/2017 to cover all calendar years from company reports.

ER extracted data from disclosure reports and annual accounts (Appendix_3–4: https://doi.org/10.15125/BATH-00904). PO checked the extraction of 20% and 25% of randomly selected

documents of each type, finding no discrepancies (Appendix_5–6: https://doi.org/10.15125/BATH-00904).

When integrating the drug company and patient organisation data sets, we excluded 14 (3.4%) of 416 organisations reporting no income between 2012 and 2016 (Appendix_7–9: https://doi.org/10.15125/BATH-00904). For the remaining 402 (96.4%) organisations, reporting total incomes and expenditures worth £16,698,062,806.3 and £16,583,716,163.1, respectively, we converted the calendar into financial years. We turned reports covering months up to June into the previous calendar year, and the rest into the current calendar year; we also turned reports without month end date into the previous calendar year, following the distribution of reports providing month end dates. As some of the patient organisation data fell outside of the time range covered by the calendar years from drug company disclosure reports, we excluded yearly incomes and expenditures, worth £1,975,107,486.5 (11.8%) and £1,994,952,884.8 (12.0%), respectively. We further excluded 3 (0.7%) organisations, with a total income and expenditure worth £218,390.5 (0.001%) and £188,887.2 (0.001%), respectively, as their total income was less than the industry payments received. Possible reasons for this anomaly include companies or organisations reporting some of the income or payments in different years. Finally, we excluded one organisation reporting no expenditure during the study period, perhaps reflecting its inactivity.

The exclusions of patient organisations related to data set integration (Appendix_8, Appendix_1: https://doi.org/10.15125/BATH-00904) also necessitated the exclusion of 143 (3.4%) drug company payments, worth £1,413,343.1 (2.6%). The resulting data set used for analysis comprised 4,092 payments, worth £52,658,111.1, made by 62 companies to 398 organisations reporting a total income and expenditure of £14,722,731,449.2 and £14,588,574,391.1, respectively (Appendix_10: https://doi.org/10.15125/BATH-00904).

Patient organisation characteristics

We collected online information on eight patient organisation characteristics which we used as predictor variables for explaining the level of financial dependency (Appendix_10–24: https://doi.org/10.15125/BATH-00904).

- Organisational goal—single purpose (exclusive focus on: advocacy; funding of other organisations; education; and patient support) or multipurpose (any combination of the single purposes).
- Members—present or absent.
- Volunteers—present or absent.
- Geographical scope of activity—local; regional; country forming part of the UK; UK; international or global; and not clearly specified.
- Headquarter location (country)—England, Scotland, Wales and Northern Ireland.
- Headquarter location (postcode)—converted into latitude and longitude and subsequently used to calculate distances from the centres of London, Edinburgh, Cardiff and Belfast (Appendix_22–24: https://doi.org/10.15125/BATH-00904).
- Disease area—website descriptions coded using the ICD10 (2016 edition) disease classification.
- Expenditure/income ratio—expenditure divided by income for the entire study period.

Data analysis

We analysed and visualised data in R. We calculated two outcome variables (Appendix_10: https://doi.org/10.15125/BATH-00904): the percentage of patient organisation income received from all drug companies (*general dependency*); and the percentage of income received from the top donor (*company-specific dependency*).

For continuous predictor variables (headquarter location and expenditure/income ratio), we describe the distribution of the outcome variables in each quartile of the predictor variable. For categorical predictor variables (all other variables), we show the distributions of the outcome variables for each value of the predictor.

We constructed linear regression models for *general* and *company-specific dependency*. We log-10 transformed the percentage dependency values to achieve distributions approximating normal distribution (Appendix_25: https://doi.org/10.15125/BATH-00904). The regression models cover the entire period from 2012 to 2016 because all but one predictor variable (expenditure/income ratio) were considered constant over time and because most organisations had highly variable annual dependency levels resulting from changes in industry payments (Appendix_26–28: https://doi.org/10.15125/BATH-00904).

Data on the disease areas were recoded as dummy variables of the ICD10 groups from ICD10_1 to ICD10_25. In the regression models, only ICD codes which had at least 10 corresponding organisations were included. We also omitted disease areas or issues not appearing in the ICD10, as this dummy variable was heterogeneous and difficult to interpret.

The initial model included all predictor variables, with the reference for categorical variables reflecting those stated in the hypotheses (multipurpose organisations; no members; no volunteers; headquarter location in England; not representing a given disease area). This method of variable entry was preferable as no prior research suggested a hierarchy of the variables regarding their importance for explaining *general* or *company-specific dependency*. To select the most relevant predictors in the final models, backward stepwise regression was used, with significance levels of 0.10 and 0.05 for removing and adding parameters, respectively.

Each regression model passed relevant diagnostics: linearity assumption, homogeneity of variance of the residuals, normality of residuals, outliers and high leverage points, and influential values.

FINDINGS

Descriptive analysis

Distribution of patient organisation income and industry payments

The values of patient organisation income, all industry payments and top-donor payments varied widely, with medians of £2,077,125.8 (IQR, £583,565.9-£8,959,661.7), £20,052.3 (IQR, £2,100.1-£93,039.1) and £15,225.0 (IQR, £2,015.0-£57,658.0), respectively (Appendix_29: https://doi.org/10.15125/BATH-00904).

Patient organisation income was highly concentrated, with the bottom 80.0% of organisations receiving only 42.1% of income (Appendix_30: https://doi.org/10.15125/BATH-00904). Similarly, the bottom 80.0% of organisations accumulated only 38.2% and 44.5% of all industry payments and top-payer payments, respectively (Appendix_30: https://doi.org/10.15125/BATH-00904).

Some organisations consistently received more industry payments than their cumulative share of income would suggest, with those generating the bottom 10.0% of income receiving 78.0% of payments (Appendix_31: https://doi.org/10.15125/BATH-00904). Nevertheless, organisations usually received a share of top-donor payments smaller or similar than suggested by their cumulative income share. Notably, those receiving the bottom 70.0% of the income received 66.0% of top-donor payments (Appendix_31: https://doi.org/10.15125/BATH-00904). Finally, organisations received a share of top-donor payments only slightly higher than indicated by their overall share of industry payments. For instance, those receiving the bottom 80% of payments also received 84.0% of top-donor payments.

Extent of financial dependency

The levels of *general* and *company-specific dependency* varied, with respective medians of 0.8% (IQR, 0.1%-6.0%) and 0.6% (IQR, 0.1%-4.3%; Appendix_29: https://doi.org/10.15125/BATH-00904). However, most organisations had relatively low dependency; as many as 322 (80.9%) and 341 (85.7%) of the 398 organisations displayed *general* and *company-specific dependency* lower than 10%, respectively (Figure 1a, Appendix_29: https://doi.org/10.15125/BATH-00904). Notably, 192 organisations (48.2%) had *general* dependency equal to *company-specific dependency* and therefore received payments from one donor (Appendix_32: https://doi.org/10.15125/BATH-00904).

Given the low value of the third quartiles, the cut-off point of 1.5 times the IQR above the third quartile was only 14.9% and 10.6% for *general* and *company-specific dependency* (Figure 1b). Consequently, of the 398 organisations 51 (12.8%) and 56 (14.1%) were above this cut-off point for *general* and *company-specific dependency*, respectively (see the dots beyond the whiskers range in Figure 1b). The share of exceptional cases of high dependency was lower based on the income share of all industry payments or top-donor payments; only 18 (4.5%) and 8 (2.0%) organisations had *general* and *company-specific dependency*, respectively, above 50%.

Differences in levels of financial dependency

We now summarise the distribution of *general* and *company-specific dependency* alongside each predictor variable from hypotheses 3–10 (Appendix_33: https://doi.org/10.15125/BATH-00904).

Considering organisational goals, most of the investigated 398 organisations were multipurpose ($n = 267$), followed by single-purpose organisations focussing on patient support ($n = 70$), advocacy ($n = 29$), funding other organisations ($n = 23$), or education ($n = 9$). Advocacy organisations had the highest median *general* and *company-specific dependency* (6.4% and 4.3%, respectively), with maximum values of 80.2% and 47.1%. Support and multipurpose organisations included outliers lower than 96.9% and 81.2% (*general dependency)* and 89.3% and 73.2% (*company-specific dependency*). However, those focussing on funding or education showed consistently low financial dependency (Figure 2a).

Most organisations reported having members ($n = 264$) and volunteers ($n = 336$). Higher *general* and *company-specific dependency* levels were usually found in organisations with members (Figure 2b) but lower in those with volunteers (Figure 2c).

Among organisations reporting a geographical scope of activity, those with the UK ($n = 241$) or international scope ($n = 74$) usually had higher *general* and *company-specific* dependency than

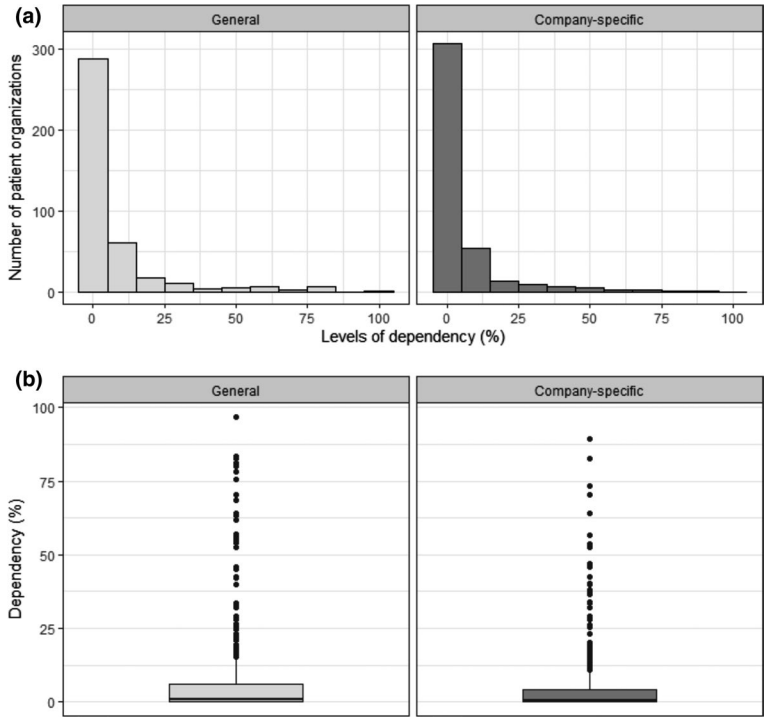

FIGURE 1 Distribution of general and company-specific financial dependency on a histogram (a) and on a box and whisker plot (b). The interpretation of the box plots is as follows: box = interquartile range (difference between the third and the first quartile); thick horizontal line within the box = median (second quartile); whiskers (lines extending parallel from the boxes) = the third quartile plus 1.5 times the interquartile range; dots = individual outliers beyond the whiskers range

those with a local ($n = 20$), regional ($n = 34$) or country-level scope ($n = 27$). The highest median dependency level was observed in those with no specified geographical scope ($n = 2$; Figure 3a).

Considering headquarter locations, patient organisations were mostly located in England ($n = 361$), followed by Scotland ($n = 27$), Wales ($n = 8$) and Northern Ireland ($n = 2$). Although those located in Wales often had the highest dependency levels, outliers were identified everywhere except for Northern Ireland (Figure 3b). Headquarter distance from country capital was in the 0.5–261 miles range, with a median of 17.5 miles (Appendix_33: https://doi.org/10.15125/BATH-00904). Patient organisations from the first quartile of the headquarter distance from country capitals had considerably lower dependency levels than those from the fourth quartile (located furthest away from the capitals). However, organisations from the second quartile had higher dependency levels than those from the third quartile (Figure 3c).

Regarding the 5-year expenditure/income ratio, most patient organisations spent their income entirely or almost entirely, and sometimes spending even exceeded the income (Appendix_33: https://doi.org/10.15125/BATH-00904). With no reason to doubt the quality of the financial data provided by patient organisations having the 5-year expenditure/income ratio exceeding one, we view these results not as administrative errors but indicators of financial imbalance within the study period (with net loans or reserves). Surprisingly, organisations with the lowest expenditure/income ratio (first quartile) had the highest financial dependency levels, followed by those with the highest expenditure/income ratio (fourth quartile). Contrastingly, the lowest financial

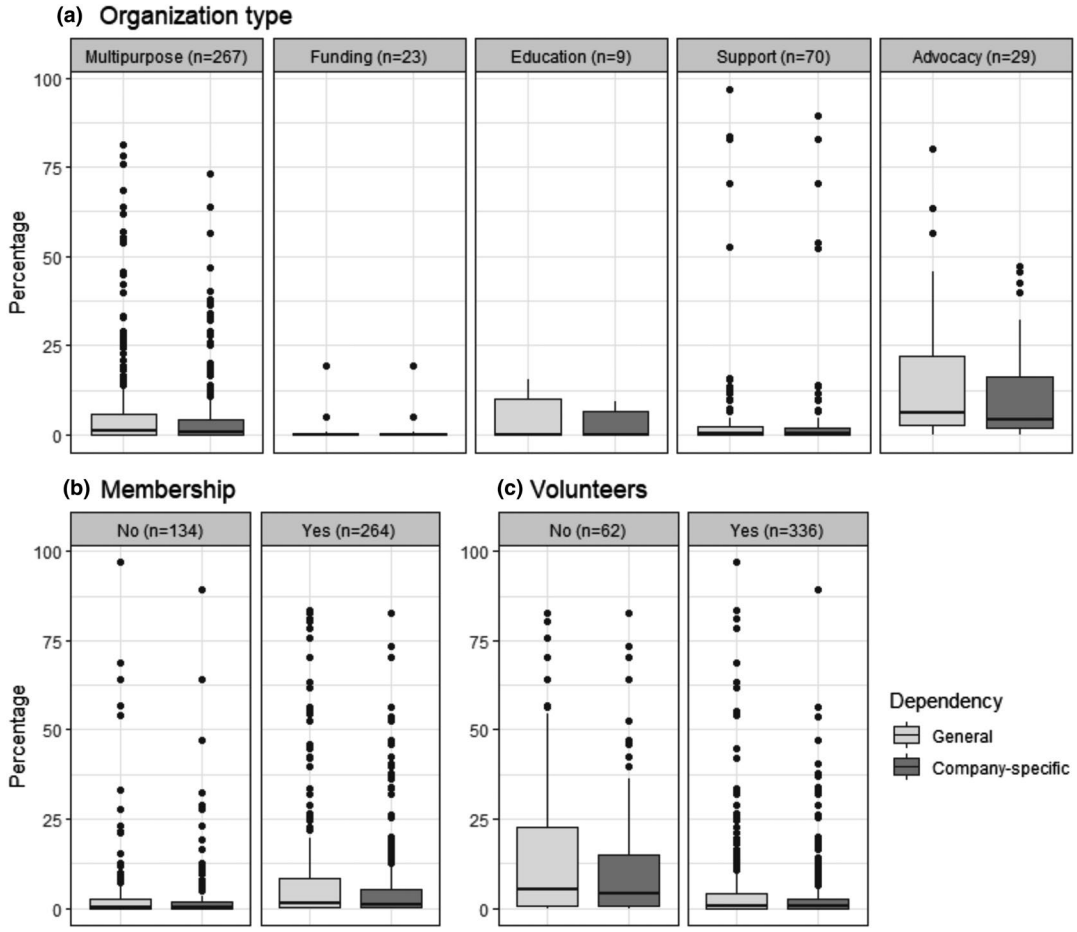

FIGURE 2 General and company-specific financial dependency levels reported by organisation goals (a), the presence of members (b) and volunteers (c). The interpretation of the box plots is as follows: box = interquartile range (difference between the third and the first quartile); thick horizontal line within the box =median (second quartile); whiskers (lines extending parallel from the boxes) = the third quartile plus 1.5 times the interquartile range; dots = individual outliers beyond the whiskers range

dependency was found in those with expenditure/income ratios in the 0.97–1.03 range (Figure 3d).

Most of the patient organisations represented a specific disease field, with 10 or more focussing on neoplasms (ICD10 02, $n = 79$); infectious and parasitic diseases (ICD10 01, $n = 41$); diseases of the nervous system (ICD10 06, $n = 40$); endocrine, nutritional, and metabolic diseases (ICD10 04, $n = 27$); mental and behavioural diseases (ICD10 05, $n = 21$); diseases of the musculoskeletal system and connective tissue (ICD10 13, $n = 18$); diseases of the blood and immune system (ICD10 03, $n = 18$); cardiovascular diseases (ICD10 09, $n = 18$); factors influencing health status and contact with health services (ICD10 21, $n = 14$); congenital anomalies (ICD10 17, $n = 13$); diseases of the digestive system (ICD10 11, $n = 13$); diseases of the genitourinary system (ICD10 14, $n = 13$); and symptoms and signs not classified elsewhere (ICD10 18, $n = 12$). However, several patient organisations could not be linked to a single disease area (no specific ICD10 range for 50 organisations; multiple disease areas for 9 organisations).

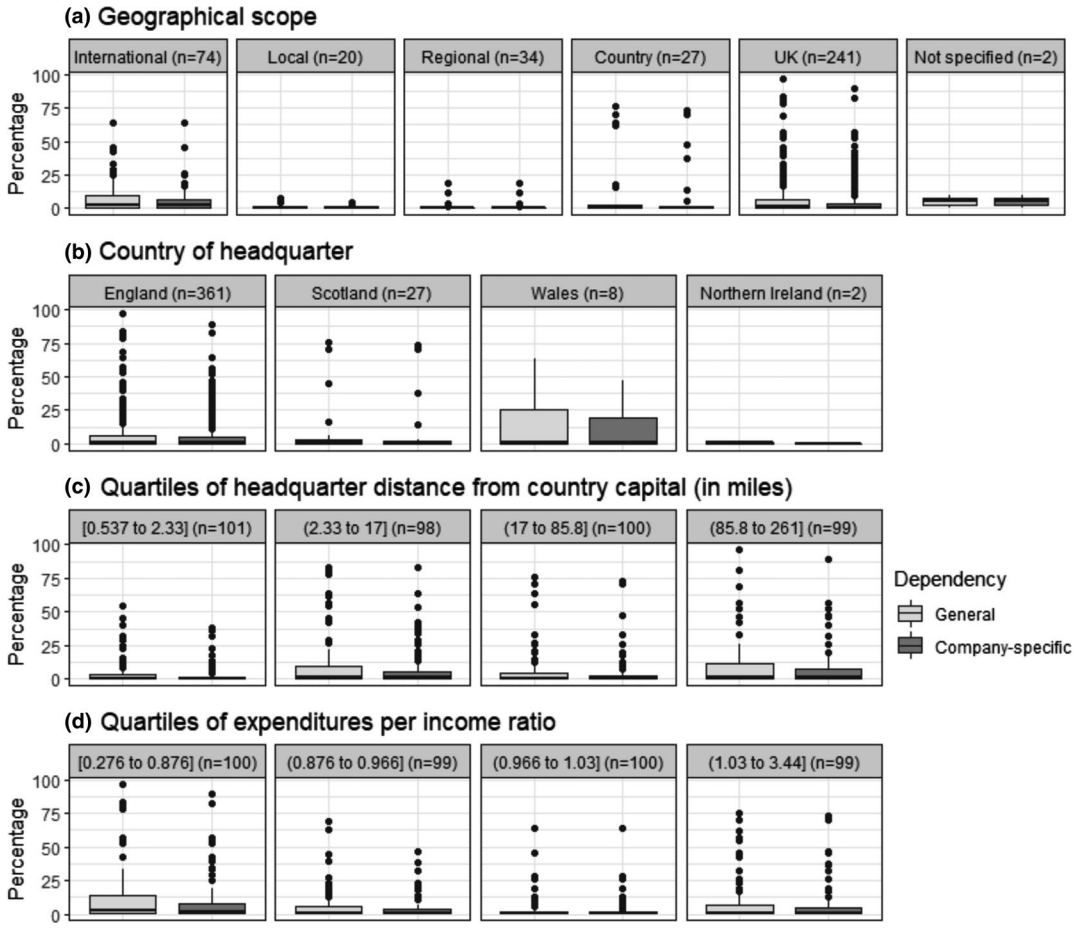

FIGURE 3 General and specific financial dependency levels by geographical scope of activity (a), country of headquarter (b), quartiles of distance from country capital, quartiles of expenditure/income ratio. The interpretation of the box plots is as follows: box = interquartile range (difference between the third and the first quartile); thick horizontal line within the box = median (second quartile); whiskers (lines extending parallel from the boxes) = the third quartile plus 1.5 times the interquartile range; dots = individual outliers beyond the whiskers range

Overall, Figure 4 shows the distribution of *general* and *company-specific dependency* across disease areas, with factors influencing health status and contact with health services (ICD10 21) having the lowest and diseases of blood and immune system (ICD10 03) the highest dependency levels, respectively.

Regression models

Explanatory model for general dependency

The final model of *general dependency* (Table 1) included organisational goal, distance from country capital, membership, volunteers, and three disease areas: haematology–immunology

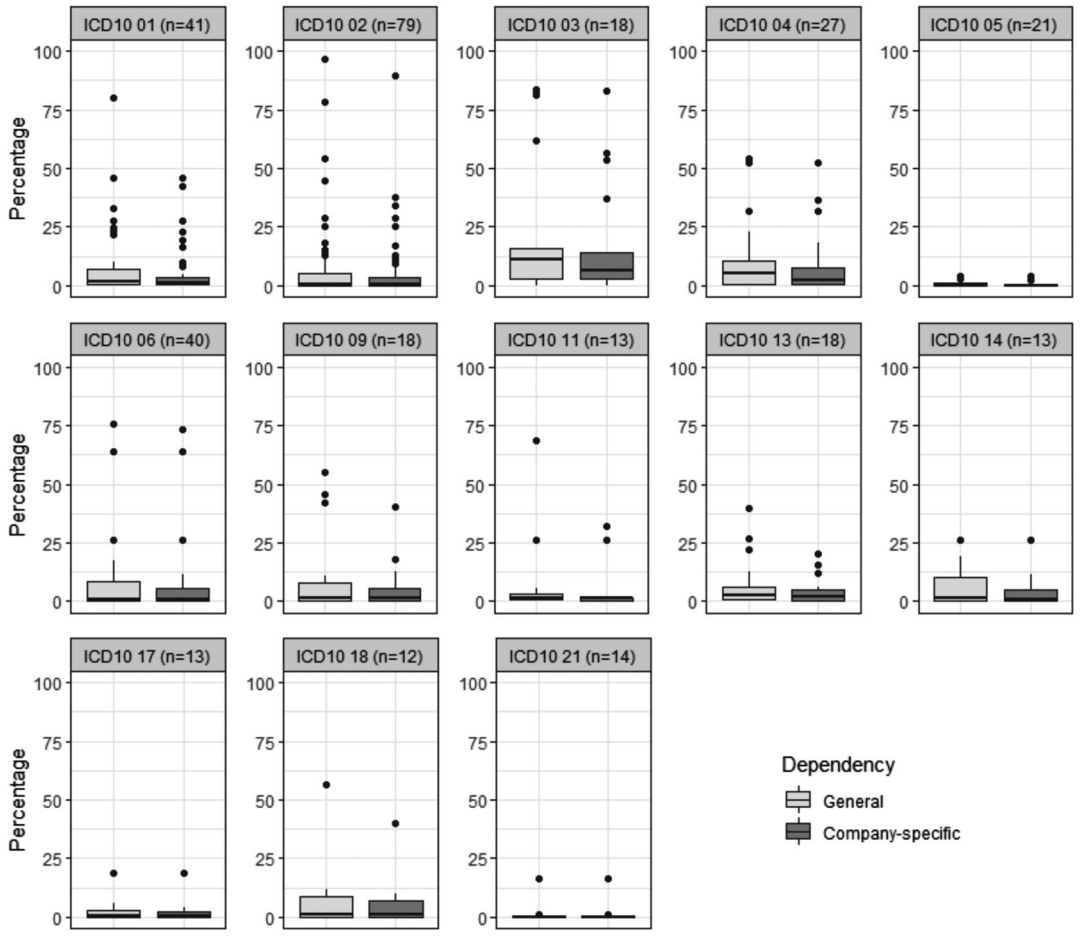

FIGURE 4 General and specific financial dependency levels by disease areas. The interpretation of the box plots is as follows: box = interquartile range (difference between the third and the first quartile); thick horizontal line within the box =median (second quartile); whiskers (lines extending parallel from the boxes) = the third quartile plus 1.5 times the interquartile range; dots =individual outliers beyond the whiskers range

(ICD10 03), mental and behavioural diseases (ICD10 05), and factors influencing health status and contact with health services (ICD10 21).

The statistically significant predictors of lower *general dependency* included the sole organisational goals of funding of other organisations or supporting patients (compared with multipurpose organisations); having volunteers (compared to not having volunteers); and the activity focus on mental and behavioural disorders (ICD10 05), or on factors influencing health status and contact with health services (ICD10 21; compared with the focus on other conditions). However, significantly larger *general dependency* characterised organisations with members; larger headquarter distance from a country capital; the sole organisational goal of patient advocacy; and the activity focus on haematology–immunology (ICD10 03). The final regression model explained 21.1% of the variance in the data, $F(10, 387) = 10.24$, $p = 0.0001$ (Appendix_34: https://doi.org/10.15125/BATH-00904).

As calculating the values of *general dependency* required computing the value of all industry payments for each organisation, we constructed a separate explanatory model for this parameter (Appendix_35, 36: https://doi.org/10.15125/BATH-00904).

TABLE 1 Linear regression results for the final model on log normalised (log-10) general dependency

Parameter	Coefficient [95% CI]	*p* Value
(Intercept)	−0.221 [−0.409 to −0.032]	**0.022**
Organisation goal		
Multi-purpose	Reference	
Funding	−0.835 [−1.353 to −0.317]	**0.002**
Education	0.054 [−0.732 to 0.839]	0.893
Support	−0.387 [−0.701 to −0.072]	**0.016**
Advocacy	0.495 [0.011–0.98]	**0.046**
Headquarter distance from country capital in miles	0.002 [0–0.004]	**0.029**
Membership (reference: yes)	−0.279 [−0.539 to −0.019]	**0.036**
Volunteers (reference: yes)	0.673 [0.329–1.017]	**<0.001**
ICD10 03 in focus (reference: no)	0.971 [0.414–1.528]	**0.001**
ICD10 05 in focus (reference: no)	−0.840 [−1.355 to −0.325]	**0.001**
ICD10 21 in focus (reference: no)	−0.667 [−1.295 to −0.04] 0.038	**0.038**

Note: P values below 0.05 are typed in bold

ICD10 03—diseases of blood and immune system ($n = 17$).

ICD10 05—mental and behavioural diseases ($n = 19$).

ICD10 21—factors influencing health status and contact with health services ($n = 14$).

Explanatory model for company-specific dependency

The final model of *company-specific dependency* (Table 2) included organisational goal, distance from country capital, membership, volunteers and two disease areas—diseases of blood and immune system (ICD10 03) and mental and behavioural disorders (ICD10 05).

The statistically significant predictors of lower *company-specific dependency* included the sole organisational goals of funding other organisations or supporting patients (compared with multipurpose organisations); having volunteers (compared with not having volunteers); and activity focus on mental and behavioural disorders (ICD10 05; compared with focus on other conditions). In contrast, significantly higher *company-specific dependency* was found in organisations with membership, larger headquarter distance from a country capital and an activity focus on haematology–immunology (ICD10 03). Additionally, borderline statistical significance for larger *company-specific dependency* characterised organisations with the sole organisational goal of advocacy ($p = 0.055$). The final regression model explained 18.3% of the variance in the data, $F(9, 388)=10.88$, $p = 0.0001$ (Appendix_37: https://doi.org/10.15125/BATH-00904).

DISCUSSION

Our article shows the minimum extent of patient organisations' dependency on drug company funding in the UK. It also identifies the profiles of organisations most likely to be financially dependent and therefore potentially exposed to co-optation to industry agendas.

Consistent with **hypothesis 1**, organisations had *general dependency* similar, on average, to those from the only available comparator European study. While 28 of 398 (7.0%) UK organisations

TABLE 2 Linear regression results for the final model on log normalised (log-10) company-specific dependency

Parameter	Coefficient [95% CI]	*p* Value
(Intercept)	−0.395 [−0.577 to −0.213]	**<0.001**
Organisation goal		
Multi-purpose	Reference	
Funding	−0.763 [−1.266 to −0.26]	**0.003**
Education	0.073 [−0.688 to – 0.834]	0.851
Support	−0.364 [−0.667 to −0.061]	**0.019**
Advocacy	0.462 [−0.008–0.932]	0.055
Headquarter distance from country capital in miles	0.002 [0.000–0.004]	**0.014**
Membership (reference: yes)	−0.261 [−0.513 to −0.009]	**0.043**
Volunteers (reference: yes)	0.726 [0.393–1.06]	**<0.001**
ICD10 03 in focus (reference: no)	1.013 [0.473–1.553]	**<0.001**
ICD10 05 in focus (reference: no)	−0.748 [−1.247 to −0.25]	**0.003**

Note: P values below 0.05 are typed in bold

ICD10 03—diseases of blood and immune system ($n = 17$).

ICD10 05—mental and behavioural diseases ($n = 19$).

reported industry payments exceeding 20% of income, the respective figure was 4 of 39 (10.3%) in Finland (Hemminki et al., 2010). However, *general dependency* was generally lower than in the United States, as measured by the share of organisations with industry funding lower than 10% (80.9% in the UK vs. 34% in the United States; McCoy et al., 2017) or the median value of *general dependency* (0.8%, IQR, 0.1%–6.0%, in the UK vs. 45%, IQR, 0%–100% in the United States; Rose et al., 2017). This contrast suggests that patient organisations are more important to the industry in the United States, consistent with a decisive shift towards neoliberalism and consumerism in US drug regulation, promoting extensive coalitions with drug access-oriented patient organisations (Davis & Abraham, 2013, pp. 103–106). However, these comparisons require cautious interpretation given the differences in the funder types (the US studies considered a biotechnology sector beyond pharmaceuticals), the funding form (unlike the Finnish data, ours included indirect support), and the fact that, unlike our data, the US and Finnish studies could include organisations without industry funding. Finally, in neither country a legal obligation existed to disclose payments, which translates into potential under-reporting; as already noted, payment reports were unavailable for nearly 40% of companies committing to disclosing payments to patient organisations in the UK.

Contrary to **hypothesis 2**, *company-specific dependency* seems to have increased compared with the partial UK data from over a decade ago. Although 85.7% of organisations from our sample had funding from the top donor lower than 10% of their income, the previous study identified a similar share of funding from three donors (Jones, 2008). Given the diminishing availability of alternative funding (Baggott & Jones, 2015), this pattern indicates increasing risks to organisational autonomy (Parker et al., 2019).

The identified shares of organisations with exceptionally high financial dependency partially supported both **hypotheses 1 and 2**. Considering the statistical definition of outliers, the shares were higher than the expected 10% of the total number of organisations. However, this followed

the typically low dependency levels, which made organisations with higher dependency stand out more. Conversely, using the proportion of 50% of industry funding in overall income, the share of outliers was lower than the 10%. While our calculations are sensitive to the chosen cut-off points, the clear presence of outliers reflects earlier UK and international research using crucial case studies (Ball et al., 2006; Herxheimer, 2003, p. 1209; O'Donovan, 2007; Wood, 2000, p. 83).

Financial dependency differed according to organisational characteristics. Those with the highest levels were advocacy organisations; had members but not volunteers; an international scope of activity; were in Wales, and generally further away from the UK country capitals; and represented diseases of the blood and immune system.

However, only some organisational characteristics significantly predicted financial dependency. Consistent with **hypothesis 8**, organisations in remote areas had significantly higher dependency. Therefore, geographically determined resources may be vital for diversifying organisations' incomes and potentially replacing industry funding. Without direct comparative data, this interpretation corresponds with prior research showing local organisations have smaller incomes (Baggott et al., 2005, p. 96).

Hypothesis 10 received mixed support as only several disease areas significantly predicted dependency. Significantly higher dependency characterising organisations representing diseases of the blood and immune system might reflect many recent drug launches in this area, for example, for bleeding disorders, such as haemophilia (Mulinari et al., 2020b). These launches mean that companies have marketing budgets which can be spent on funding patient organisations (Mulinari et al., 2020b; Parker et al., 2019). Further, the relative rarity of these disorders, as represented in our database, means more difficulties in accessing alternative funding. Conversely, significantly lower dependency levels of mental health organisations reflect few drug launches in this field and therefore its diminished commercial attractiveness (Brady et al., 2019; Mulinari et al., 2020b). Contrasting with concerns about cancer patient advocacy being shaped by the industry (Batt, 2017; Davis & Abraham, 2013, pp. 166–171), organisations representing patients with neoplasms did not have significantly higher dependency. This finding does not contradict the importance of cancer patient organisations for drug companies (Mulinari et al., 2020b; Ozieranski et al., 2019), but might demonstrate the high prevalence and societal status of cancer, resulting in an unprecedented availability of funding, also from alternative sources (Baggott et al., 2005, pp. 53–58). Indeed, three of the cancer patient organisations from our study, Cancer Research UK, Macmillan Cancer Support and Marie Curie Cancer Care, are top UK charity fundraisers (Charity Financials, 2017). Another possible interpretation is that some organisations from our database represented cancers not associated with new drug launches and/or were primarily treated with drugs no-longer protected by patents.

Hypothesis 3 was partially supported as not all organisations with a specific activity focus had lower dependency than multipurpose ones, suggesting that only certain types of activity made them more likely to develop financial dependency. Significantly lower dependency in organisations concentrating on funding other organisations can be explained by the industry's preference to target organisations directly relevant to its agendas (Batt, 2017, pp. 188–192; Parker et al., 2019) and not those making their own funding choices. Further, significantly lower dependency in organisations focussing on patient support might indicate that industry funding constituted a small share of their otherwise small incomes, therefore resulting in lower dependency. However, contrary to **hypothesis 3**, advocacy organisations had significantly higher *general dependency* levels, with *company-specific dependency* displaying borderline significance. This finding corresponds with the key roles played by patient advocacy groups in industry marketing and lobbying

campaigns (Batt, 2017, pp. 140–143; Davis & Abraham, 2013, pp. 107–109, 166–171, 225–227) and widespread conflicts of interest in organisations seeking to shape pharmaceutical policy (Mandeville et al., 2019). The financial dependency of the increasingly influential patient advocacy movement raises concerns around the possibility of shaping health policy in ways prioritising commercial interests over public health needs (Batt, 2017, pp. 169–183; Davis & Abraham, 2013, pp. 196–198, 231–234).

Consistent with **hypothesis 5**, organisations without volunteers had significantly higher dependency, suggesting their contributions to organisational functioning, especially via time, free labour and expertise (Baggott et al., 2005, pp. 97, 99, 104), were also crucial for maintaining autonomy from industry. Perhaps surprisingly, organisations without members had significantly lower dependency, contrary to **hypothesis 4**. This might indicate that the resources that members bring to the day-to-day running of organisations—especially financial contributions and networking—were less important than expected in compensating for industry funding than the resources associated with volunteers. Conversely, organisations with members, especially patients or caregivers, may be more attractive for the industry and therefore have higher shares of its funding in their incomes. For example, membership can help demonstrate the representativeness of organisations or be a source of narratives that could be used in marketing or lobbying campaigns (Ozieranski & King, 2017, pp. 595–596).

Finally, some variables hypothesised to be important for predicting financial dependency had to be dropped from the regression models. Location in different UK countries (**hypothesis 7**), the geographical scope of activity (**hypothesis 6**) and the expenditure/income ratio (**hypothesis 9**) made no apparent difference in determining whether organisations were financially dependent.

Overall, our regression models explained around a fifth of the values of financial dependency, suggesting other potentially important variables, including those related to the patient organisations' 'symbolic resources', which we could not measure in this study.

CONCLUSIONS

Considering the limitations of our data, our findings are best summarised by a combination of the disease–politics and patient–industry complex positions. Consistent with the former perspective, unless industry funding was heavily underreported, the prevalent relatively low financial dependency levels suggest that many organisations command alternative resources, therefore making widespread astroturfing implausible. Notably, reflecting the emphasis disease–politics theory puts on civil society credentials as new social movements, volunteers seemed a crucial organisational resource. Further potential for countering financial dependency—not explored by our study—involves symbolic resources, including public trust.

However, rejecting the patient–industry complex position is unwarranted as it has never specified a necessary share of financially dependent organisations. Moreover, as we have mentioned, the possibility of under-reporting of financial links remains and cannot be discounted, especially in view of ongoing concerns that clinical trials are massively underreported in the pharmaceutical sector, although larger companies are typically more compliant with reporting requirements (Axson et al., 2021; Goldacre et al., 2018). That said, our data suggest that likely pockets of a patient–industry complex exist in the subsection of organisations highly reliant on industry funding. One key feature of such a complex would be its orientation around the commercial interests of specific companies as nearly half of the patient organisations had a just one industry funder. The key pillar of the patient–industry complex would be advocacy

organisations, reflective of the argument about the uses of patient organisations as 'assimilated allies' important for influencing other 'stakeholders' involved in 'market access' for new drugs.

Nevertheless, reflecting analyses of the association between industry payments and physicians' prescribing, financial dependency may not necessarily involve a dose–effect relationship, that is, more financially dependent organisations being, on average, more aligned with industry interests (Nguyen et al., 2019; Yeh et al., 2016); it is also possible that even small gifts have a significant impact on organisations (Katz et al., 2003; Mintzes, 2007). Perhaps even more importantly, it is unclear whether financial dependency is necessary for the patient–industry complex to emerge after all. Indeed, some of the non-financial organisational links, including ideology, may be a more pertinent source of influence.

The scope of the patient–industry complex might be further examined—using both qualitative and quantitative methods—by considering different organisational links between the two sides, including at the level of specific projects and activities undertaken by patient organisations. What is crucial here is examining the possible dialectic relationships between key dimensions of the patient–industry complex, for example, receiving industry funding and developing a consumerist ideology. Such investigation could reveal that while sometimes accepting industry funding may facilitate access-oriented consumerist orientations, causality may well go in the other direction (Abraham, 2010, pp. 611–613). No less important is considering the other side of the funding relationship, that is, the impact of patient organisations' orientations and activities on company decisions about who to fund (Batt, 2017, pp. 140–143).

PATIENT CONSENT STATEMENT

Not applicable.

PERMISSION TO REPRODUCE MATERIAL FROM OTHER SOURCES

Not applicable.

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CONFLICT OF INTEREST

SM's partner is employed by PRA Health Sciences, a global Contract Research Organization whose costumers include many pharmaceutical companies. PO's PhD student was supported by

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AUTHOR CONTRIBUTION

Piotr Ozieranski: Conceptualization (lead); Data curation (equal); Formal analysis (equal); Funding acquisition (equal); Investigation (equal); Methodology (equal); Project administration (equal); Resources (lead); Software (supporting); Supervision (lead); Validation (supporting); Visualization (supporting); Writing-original draft (lead); Writing-review & editing (lead). **Janos Pitter:** Conceptualization (equal); Data curation (supporting); Formal analysis (lead); Investigation (equal); Methodology (equal); Project administration (supporting); Resources (supporting); Software (lead); Supervision (supporting); Validation (lead); Visualization (lead); Writing-original draft (equal); Writing-review & editing (supporting). **Emily Rickard:** Conceptualization (supporting); Data curation (lead); Formal analysis (supporting); Funding acquisition (supporting); Investigation (lead); Methodology (supporting); Project administration (lead); Resources (equal); Software (supporting); Supervision (supporting); Validation (supporting); Visualization (supporting); Writing-original draft (equal); Writing-review & editing (equal). **Shai Mulinari:** Conceptualization (equal); Data curation (supporting); Formal analysis (supporting); Funding acquisition (lead); Investigation (equal); Methodology (equal); Project administration (lead); Resources (lead); Software (supporting); Supervision (supporting); Validation (supporting); Visualization (supporting); Writing-original draft (equal); Writing-review & editing (equal). **Marcell Csanadi:** Conceptualization (lead); Data curation (equal); Formal analysis (lead); Funding acquisition (supporting); Investigation (equal); Methodology (lead); Project administration (equal); Resources (supporting); Software (equal); Supervision (supporting); Validation (equal); Visualization (supporting); Writing-original draft (equal); Writing-review & editing (supporting).

ETHICAL APPROVAL

The ethical implications of the study presented in this article were reviewed and approved via a peer ethics review process at the Department of Social and Policy Sciences, University of Bath in April 2016. The Social Sciences Research Ethics Committee at the University of Bath confirmed in April 2019 that a full ethical approval was not required.

DATA AVAILABILITY STATEMENT

The authors agree to share the data underpinning this study. We present it in the form of online supplements signposted throughout the main body of the article. They can be accessed via a web link and are stored in the University of Bath Research Data Archive. The supplementary data pose no risk to anonymity of individuals. The data set can be cited as: Ozieranski et al., 2021.

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