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Mulinari, Shai; Pashley, Dylan; Ozieranski, Piotr

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PO Box 117
221 00 Lund
+46 46-222 00 00



Advancing international comparison of pharmaceutical industry funding of patient advocacy: Focus on Denmark

Shai Mulinari^{a,*}, Dylan Pashley^a, Piotr Ozieranski^b

^a Department of Sociology, Faculty of Social Sciences, Lund University, Lund, Sweden

^b Department of Social and Policy Sciences, University of Bath, Bath, United Kingdom

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ABSTRACT

Pharmaceutical industry funding of patient organizations raises ethical challenges related to patient engagement in healthcare due to fears of commercial agendas influencing patient advocacy and creating industry-driven inequalities across patient organizations. We contribute to an international body of knowledge on patient organization–industry relations by analyzing all payments reported by companies in Denmark over a six-year period, 2014–2019. We performed descriptive analyses calculating the number, value, and distribution of payments for various units of analysis: all companies and patient organizations; individual companies and patient organizations; and the broader disease area (e.g., cancer) and narrower disease (e.g., breast cancer). Fifty-one companies reported paying €8,826,916 to 84 patient organizations. As in previously studied countries, the funding was dominated by a relatively small number of funders and recipients, and commercially high-profile diseases attracted most of the funding. Nevertheless, our study also highlighted the arguably concerning dominance of one company in Denmark, both at the level of overall funding and in funding specific patient organizations, during a time of great policy contention surrounding one of its drugs, the world's top-selling medicine; i.e., switching patients to cheaper biosimilars to save big money for the healthcare system. Patient organizations have reasons to rethink some collaborations with companies, especially during policy contentions, and governments should ensure equitable funding to counteract risks posed by the concentration of industry funding.

1. Introduction

In recent years, there has been much debate about the ethics and governance of the commercial funding of health and patient advocacy [1,2]. Perhaps the prime example is pharmaceutical companies' widespread funding of patient organizations [3]. Some have argued that pharmaceutical company funding creates insurmountable ethical challenges [4], since it tends to undermine patient organizations' independence [5] and their capacity to truly represent members' interests, especially when those interests diverge from those of their commercial sponsors [6]. Others have maintained that, on the contrary, provided appropriate ethical frameworks are in place, industry funding helps patient organizations build stronger organizational capacity [7], allowing them to better advance their members' interests including vis-à-vis the industry and the state [8].

However, a corollary of this latter argument is that pharmaceutical company funding will empower only a select number of organizations,

creating commercially patterned inequalities across patient organizations. Indeed, single-country studies of Australia [9], Sweden [10], the United Kingdom [3,11], and the United States [12] have showed how industry funding is concentrated in industry-prioritized disease areas such as cancer [13] but not in commercially less attractive ones, such as mental illness. This research also shows how some large companies dominate most of the funding and how most of the funding goes to a subset of organizations. For example, a recent Swedish study showed that in 2014–2018, 46 companies reported payments to 77 patient organizations worth at least €6.4 million, but that ten companies provided 67% and ten patient organizations received 62% of the funding [10].

However, a limitation of the existing literature on pharmaceutical company funding is the few countries investigated. With few exceptions [10,14,15], the focus has been on the Anglosphere, which follows the general trend in research on pharmaceutical industry financial relations with healthcare actors. This is an important limitation, because drawing more generalizable conclusions about funding patterns and their

* Corresponding author at: Department of Sociology, Lund University, Paradisgatan 5, Hus G, SE-22100 Lund, Sweden
E-mail address: shai.mulinari@soc.lu.se (S. Mulinari).

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possible societal consequences requires comparison across a broader sample of countries with different characteristics. For example, it is possible that commercially patterned inequalities are more pronounced in smaller countries because funding there can more easily become dominated by a few donors and recipients [16,17]. Similarly, it may be more common for individual companies to be sole industry funders of individual patient organizations in smaller countries, potentially creating a higher risk of the corporate capture of patient organization agendas. In addition, previous research has pointed to country-level factors likely to influence industry funding. In particular, both the existence of generous government funding programs [18] and a low cultural acceptance for commercial funding of civil society [19] are predicted to reduce the extent of patient organization dependence on industry funding. Finally, analysis of more countries may help identify or illustrate novel ethical and governance problems or, alternatively, show how certain recognized problems are common across many countries [20].

In this study, we analyzed the pattern of industry funding in Denmark, an example of a small European country with significant government funding of patient groups [21]. Denmark was also highlighted as having an adversarial culture vis-à-vis industry funding of patient groups compared with other European countries, although the claim that pharmaceutical industry funding was “strictly forbidden because it is considered as conflict of interest” in Denmark [19] is incorrect. Indeed, research confirms that industry funding of patient groups has existed also in Denmark [21]. More recently, a survey of 135 Danish patient advocacy groups found that 30% had received drug industry funding in the previous year, and that it accounted for 5% of organization income on average [22]. However, this figure was higher for organizations with fewer than 1000 members (6%) than for larger organizations (2%). Nonetheless, to the best of our knowledge, there are no detailed studies of the industry sponsorship of patient organizations in this country.

In addition, there are two practical advantages of carrying out this research on Denmark. First, unlike the case for most countries [12], comprehensive data on the pharmaceutical industry funding of patient organizations is readily available in Denmark [23]. These data are collated and published on a yearly basis by Denmark’s Ethical Committee for the Pharmaceutical Industry (ENLI), which is the industry-run self-regulatory authority that administers the industry-wide disclosure of patient organization funding as part of its broader mission of ensuring compliance with industry ethical rules. Second, the observed funding patterns in Denmark can be compared with those of its neighbor Sweden for which datasets for 2014–2018 were recently published [10].

2. Methods

2.1. Extraction of Payment Data from Industry Reports

Members of the Danish Association of the Pharmaceutical Industry, the Danish Generic and Biosimilars Medicines Industry Association, and the Danish Association for Parallel Importers of Medicines are automatically subject to the jurisdiction of ENLI. In addition, non-trade-group member pharmaceutical companies or organizations that have activities in Denmark can join ENLI. All companies that are subject to ENLI’s jurisdiction should submit annual disclosure reports of payments to patient organizations. ENLI assembles these reports into one industry-wide PDF spreadsheet per year. The spreadsheet has information on a per project basis regarding: (1) name of the project; (2) names of the collaborating parties; (3) type of project (e.g., disease awareness and sponsorship); (4) goal of the project (i.e., project description); (5) collaborating parties’ role in project; (6) project time frame; (7) financial value of the support; and (8) nature of any non-financial support. At the time of this study, ENLI had reports from 2017–2019 on its website but, through contact with ENLI, we gained access to the older 2014–2016 reports as well. We extracted the data from the ENLI reports

using a mixture of manual and automated tabular extraction in the Java program Tabula and in R [24]. The manual work was needed to edit the last row on many pages, since it often extended into the next page, which made automated reading difficult.

To contextualize the Danish case, we sought to compare the pattern of funding in Denmark with that in Sweden, a neighboring country that is perceived as quite similar politically and culturally when viewed from a broader international perspective [23], but that has nearly twice the population (10.2 million vs. 5.8 million). The Swedish Association of the Pharmaceutical Industry has set up a centralized and searchable on-line database to which companies should upload reports of all payments [10]. We designed a web scraper in R that automatically downloads the data into a spreadsheet. We scraped data for 2019, which were combined with the 2014–2018 database published before [10].

For both countries, some manual standardization of the extracted data was needed, for example, correcting misspellings of patient organization names and correcting variable uses of period and comma separators when reporting sums. Furthermore, to aid our comparison, non-Euro currencies were converted to Euros using daily exchange rates (or annual averages when no date information was reported) available from the “priceR” R package and were inflation adjusted to the 2018 Euro value.

2.2. Analysis of Payment Data

We performed descriptive analyses calculating the number, value, and distribution of payments. The analyses were specified beforehand to the following units of analysis used in previous single-country studies [3, 10]: all companies and patient organizations; individual companies and patient organizations; and broader disease area (e.g., neoplasm) and narrower disease (e.g., neoplasm of breast). Given our focus on the national level, we aggregated local and regional patient organizations into their parent national associations. Using the information in the payment reports, we coded payments according to their broader disease area and narrower disease using the International Classification of Diseases, 10th revision (ICD-10). For each patient organization and for each condition and disease area, we identified the supporting companies as well as the main donor’s share of the overall funding. Data were processed in Microsoft Excel and analyzed in R [24].

3. Results

3.1. Industry Payments in Denmark Compared to Sweden

The total value of reported payments was similar in Denmark and Sweden. In Denmark, 51 companies reported making payments worth €8,826,916 to 84 patient organizations between 2014 and 2019. In Sweden, 55 companies reported making payments worth €7,969,269 to 83 patient organizations. The year 2016 saw the highest value of reported payments across the industry in Denmark (€2,019,753), whereas the lowest value was in 2019 (€1,098,415) (Fig. 1A).

However, although the industry in Denmark reported roughly the same total amounts as in Sweden, the number of payments was lower in Denmark ($n = 1224$ vs. 1737) and individual payments were generally larger in Denmark (Fig. 1B). In Denmark and Sweden, respectively, there were 223 (18.1%) and 421 (24.3%) payments below €1000, 496 (40.4%) and 841 (48.6%) payments above €1000 but below €5000, and 505 (41.1%) and 381 (22.0%) payments above €5000 (Fig. 1C and 1D). However, the Swedish data included 94 reports (5.4%) that failed to report the value of the payment. Overall, the ten largest payments constituted roughly 8.6% of the total value (€759,221) in Denmark and 12.8% in Sweden (€1,019,874). The largest Danish payment was of €151,019 donated by Novartis to the Danish Psoriasis Association in 2015.

In both countries, many financial relations between companies and patient organizations seemed of limited duration rather than recurring

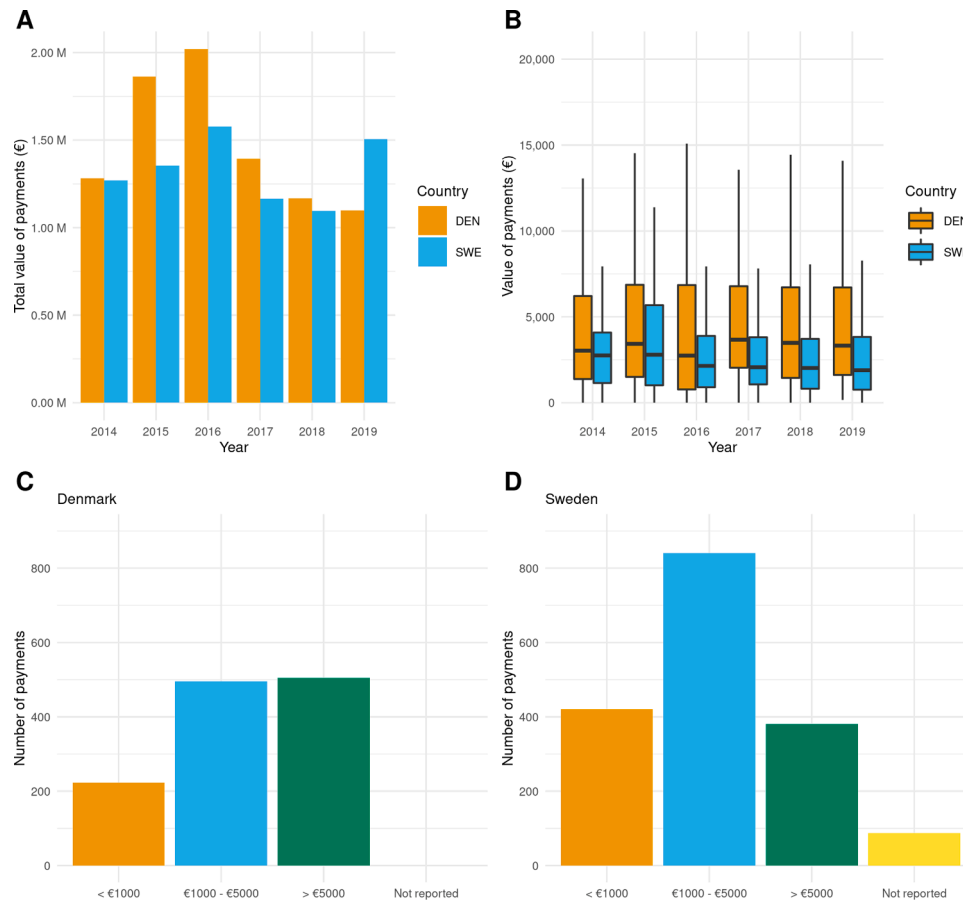


Fig. 1. Disclosed payments to patient organizations in Denmark compared with Sweden (2014–2019). Total value (A) and box-plot (B) of payments per year. (C) and (D) show the number of payments in each country below €1000, above €1000 but below €5000, and above €5000.

over several years. In Denmark, for example, there were 105 (40.1%; in Sweden 36.0%) financial relations between a company and a patient organization that occurred only in one of the study years; two of the years: 57 (21.8%; in Sweden 15.5%); three of the years: 34 (13.0%; in Sweden 15.2%); four of the years: 28 (10.7%; in Sweden 13.1%); five of the years: 24 (9.2%; in Sweden 7.2%), and in all six years: 14 (5.3%; in Sweden 12.8%). However, the accumulated monetary value of the recurring financial transfers was substantial (five years 27.0% and six years 24.5% of the overall funding in Denmark, respectively), showing that some companies and patient organizations formed long-lasting and strong relations.

3.2. Major Donors and Recipients in Denmark

Overall, the top priority in Denmark was funding cancer patient groups, to the amount of €2,222,182 (25.2%). Regarding specific diseases, the most funding went to psoriasis, at €1,019,926 (11.6%), and multiple sclerosis, at 598,108 (6.8%) (Table 1). This pattern differed somewhat from that in Sweden, where there was even more focus on cancer patient groups but less on, for example, psoriasis and multiple sclerosis (Sunburst plots in Supplemental Figs. 1 and 2).

A subset of companies was responsible for the lion's share of patient group funding in Denmark. Thus, the top ten donors provided 74.7% (€6,596,462) of the funding (Table 2). On average, the top ten donors funded 13.4 (SD = 5.2) patient organizations compared with 3.1 (SD = 2.8) patient organizations funded by the remaining 41 companies. Notably, AbbVie was alone responsible for 23.3% (€2,054,358), and which far outpaced the funding provided by any other companies, and AbbVie also reported the highest number of individual records of payments ($n = 227$; 18.5%). AbbVie made the most payments in 2016 ($n =$

Table 1

Ten diseases most funded through companies' funding of patient organizations in Denmark, 2014–2019.

Disease	Value of payments, € (%) ^a
Psoriasis	1,019,926 (11.6)
Multiple sclerosis	598,108 (6.8)
Neoplasm of bronchus and lung	474,775 (5.4)
Diabetes (Types I and II)	443,218 (5.0)
Neoplasms of lymphoid, hematopoietic, and related tissue	424,792 (4.8)
Asthma/allergic rhinitis	411,012 (4.7)
Hidradenitis suppurativa	396,016 (4.5)
Parkinson's disease	318,142 (3.6)
Neoplasm of prostate	288,115 (3.3)
Juvenile arthritis	220,942 (2.5)
Total	4,595,045 (52.1)

^a Percent of total value of payments (€8,826,916)

57; €534,271) and the fewest in 2019 ($n = 12$; €94,481), corresponding to 26.5% and 8.6% of the value of all payments in Denmark in those years, respectively.

There was also a high level of concentration of payments to a subset of patient organizations, with the top 10 recipients amassing 57.9% (€5,110,614) of the total funding (Table 3). A majority of the largest recipients relied on funding from many companies, but with much variation in the durability and strength of donor-recipient ties over the study period, e.g., Novartis funded the Psoriasis Association in all six years (€344,594) — CSL Behring only in one year (€671). On average, the top ten recipients had funding from 6.7 (SD = 3.7) drug companies

Table 2

Top ten drug companies reporting payments to patient organizations in Denmark, 2014–2019.

Company	Value of payments, € (%) ^a	n payments (%) ^b	n patient organizations funded
AbbVie	2,054,358 (23.3)	227 (18.5)	17
Novartis	1,155,512 (13.1)	101 (8.2)	22
Roche	697,639 (7.8)	146 (11.9)	15
Novo Nordisk	637,734 (7.2)	87 (7.1)	7
Bristol-Myers Squibb	454,909 (5.2)	31 (2.5)	14
Janssen-Cilag	448,773 (5.1)	58 (4.7)	12
Pfizer	390,833 (4.4)	90 (7.3)	20
Eli Lilly	280,331 (3.1)	28 (2.3)	7
Sanofi	241,901 (2.7)	42 (3.4)	10
Bayer	234,470 (2.7)	33 (2.7)	10
Total	6,596,462 (74.7)	843 (68.6)	Mean 13.4 (SD = 5.2)

^a Percent of total value of payments (€8,826,916)

^b Percent of total number of payments (1224)

Table 3

Ten patient organizations most funded by drug companies in Denmark, 2014–2019.

Patient organization (abbreviated)	Value of payments, € (%) ^a	Number of supporting companies	Main donor, € (%) ^b	Years funded by donors: mean; min-max
Psoriasis	1,073,830 (12.2)	10	Novartis, 344,594.26 (32.1)	4.0; 1-6
Diabetes	671,352 (7.6)	9	Novo Nordisk, 502,823.9 (74.9)	2.4; 1-6
Hematologic cancer	620,845 (7.0)	10	Novartis, 170,581.57 (27.5)	3.9; 1-6
Multiple sclerosis	544,617 (6.2)	8	Roche, 155,532.25 (28.6)	3.0; 1-5
Lung cancer	442,010 (5.0)	10	Bristol-Myers Squibb, 153,100 (34.6)	3.2; 1-6
Asthma and allergy	411,012 (4.7)	7	ALK Nordic, 188,237.34 (45.8)	2.7; 1-6
Hidradenitis Suppurativa	396,016 (4.5)	1	AbbVie, 396,015.73 (100)	5; NA
The Autoimmune ^c	342,675 (3.9)	1	AbbVie, 342,675.37 (100)	5; NA
Parkinson's	318,142 (3.6)	3	AbbVie, 305,909.23 (96.2)	3.7; 1-6
Prostate cancer	290,115 (3.3)	8	Astellas, 920,62.41 (31.7)	3.0; 1-6
Total	5,110,614 (57.9)	Mean 6.7 (SD = 3.7)		

^a Percent of total value of payments (€8,826,916)

^b Percent of total value of payments received by the patient organization

^c The Autoimmune is a collaboration between five patient associations representing inflammatory diseases (i.e., gout, psoriasis, hidradenitis suppurativa, Crohn's disease, and ulcerative colitis). It is separate from the Autoimmune Disease Association (FAMI), which represents a broader array of autoimmune diseases and which received €62,006 over the study period.

compared with 2.6 (SD = 2.1) drug companies for the remaining 74 organizations. The exception to this was AbbVie's relations with three patient organizations: the Hidradenitis Suppurativa, Autoimmune, and

Parkinson's associations that relied on AbbVie for all or most of their industry funding throughout the study period (Table 3; Supplemental Table 1 for year-over-year breakdown of AbbVie's funding).

4. Discussion

4.1. Comparison between Denmark and Sweden

This study considered pharmaceutical industry payments to patient organizations in Denmark, where yearly payments were in the range of roughly €1–2 million during the study period. This is similar to the amount in Sweden, but Sweden has almost twice the population (10.2 million vs. 5.8 million). In both Denmark and Sweden, government funding is readily available for patient organizations, which was predicted to reduce the need for industry funding [18]. Additionally, both Denmark and Sweden were highlighted as countries where industry funding was negatively perceived in a European comparison because of the potential for conflicts of interest [19]. From this perspective, the widespread industry funding of patient groups is surprising, and it suggests a cultural alignment with other European countries.

In Denmark, around 40% of payments were over €5000 versus around 20% in Sweden, showing an appetite for larger payments in Denmark. However, about 5% of Swedish payment reports had no information about the value of the payment, in apparent violation of industry rules [10]. Consistent with the pattern seen in other countries [3, 9,10], the Danish funding landscape was dominated by a relatively small number of funders and recipients. The ten largest funders accounted for 75% of the funding, and the ten largest beneficiaries received 58% of total funding. For Sweden, these values were 68% and 62%, respectively. The year-over-year funding data showed some major funders and recipients forming ongoing stable “business relationships” [25], characterized by substantial financial support over time, but there was also evidence of many sporadic relationships that might reflect weaker ties between some companies and patient organizations [26]. Furthermore, as in Sweden [10] and the United Kingdom [3], certain commercially high-profile disorders attracted most of the funding, including cancer and chronic inflammatory diseases, which had been the focus of many drug launches over the preceding decade [10]. In contrast, less currently commercially viable disorders, such as mental illness, remain unfunded or underfunded, likely creating commercially patterned inequalities in resource and influence across patient groups in Denmark. Responding to risks posed by the concentration of industry funding likely requires structural solutions, such as a shared corporate funding pool detached from current commercial objectives [3] and even more robust public funding of the patient group sector [26].

4.2. AbbVie's Dominance in Denmark

However, what was unique, and arguably concerning, about Denmark compared with the previously analyzed countries was the dominance of one company. This finding underscores the value of comparative, longitudinal research for understanding industry–patient organization ties. AbbVie's dominance existed both at the level of overall funding (i.e., 23% of total funding) and in funding particular patient organizations (i.e., 96–100% of the industry funding received by three of the most funded organizations). The European Federation of Pharmaceutical Industries and Associations (EFPIA) Code of Conduct, which sets the minimum standards for the industry to uphold across Europe, recognizes potential concerns with exclusive funding, stating that “Member Companies welcome broad funding and sponsorship ... from multiple sources” [27]. This is further specified in the Danish Pharmaceutical Industry's local Code of Conduct, building on the EFPIA Code, which states: “Exclusivity must not in any way be a requirement for collaboration on specific product or therapeutic areas. However, the parties may have a primary collaboration partner” [28]. The risk posed by exclusive funding is also recognized by the umbrella organization

Danish Patients, which represents 102 associations in Denmark, representing a total of 900,000 individual members. It recommends member associations not to rely on funding from a single company nor to derive more than 5% of annual income from industry [29].

However, obtaining sufficient funding from other sources may be especially difficult for small patient organizations [22]. This may help explain why, for many years, AbbVie has been the sole drug industry funder of the Danish Hidradenitis Suppurativa (HS) Association, providing almost €400,000 between 2014 and 2018, and which is implausibly 5% or less of its total income. HS is a chronic skin disease that causes abscesses and scarring of the skin, usually around the groin, buttocks, breasts, and armpits. The Danish HS Association was started in September 2013, and in June 2015 AbbVie's Humira (adalimumab) became the first HS medicine recommended for approval by the European Medicines Agency [30]. The other organization with AbbVie as sole industry funder is The Autoimmune, a collaboration between five patient associations, including the HS Association, representing patients with various chronic inflammatory diseases, all treatable with AbbVie's adalimumab. The Autoimmune received about €340,000 between 2014 and 2018 but, like the HS Association, received no AbbVie funding in 2019 – and they also received no AbbVie funding in 2020 and 2021 [31].

4.3. Policy and Ethical Concerns

In part, AbbVie's interest in supporting HS patient advocacy in Denmark may reflect the country's strategic importance in the adalimumab clinical testing program. Patient organizations can play important roles in recruitment/retention of study participants [26]. The first randomized controlled trial evaluating the efficacy and safety of adalimumab in HS was carried out in Denmark [32], and subsequent Phase II and Phase III trials had Danish study centers and a prominent Danish dermatologist among the lead investigators [33,34]. However, AbbVie's funding also likely reflects its strategy of, first, expanding adalimumab use [35] and, second, defending the Humira market from emerging competition [36]. For many years, Humira, which is extremely expensive, has been the world's top-selling medicine reaching nearly \$20 billion in annual sales in 2018, more than twice as much as the second most selling medicine. Of these sales, \$4 billion were in Europe. However, upon the October 2018 release of four lower-priced biosimilar versions of adalimumab (biosimilars are the biologic equivalents of generic drugs) in European markets, those sales began to shrink. By the end of 2019, nearly 35% of European patients had switched from AbbVie's adalimumab to a cheaper biosimilar [30].

Internationally, patient organizations supported by AbbVie have come out strongly against switching to biosimilars, for example, in France [35], Canada [36], and the United States [37], often citing worries about their safety. However, according to regulators and health professionals, biosimilars are as safe and effective as the originator products [38]. Batt et al. [4: p. 58] therefore argued that “opposing, rather than supporting, biosimilar access is an excellent example of industry distortion of the public health discourse.” Criticism was heightened in Canada after AbbVie stopped funding one patient organization that came out in support of transitioning patients to biosimilars to save money for the healthcare system [36]. The Autoimmune and other AbbVie-sponsored organizations in Denmark have also argued against adalimumab biosimilar switching [39], for example, in an open letter to health professionals in October 2018 when the biosimilars were about to be introduced [40]. Despite the opposition from the concerned patient organizations, Denmark succeeded in switching a record 90% of its use of adalimumab to new biosimilars in just three weeks, which was projected to have saved €47 million in 2019 alone [41]. This switch effectively wiped out most of AbbVie's adalimumab sales in Denmark and, seemingly, also its immediate interest in funding some of the concerned patient groups. Notably, this contrasts with AbbVie's unbroken funding of the Parkinson's disease organization – another major funding recipient – and which has continued into 2020 and 2021 [31], likely

associated with AbbVie's ongoing levodopa-carbidopa business [42].

What this example helps illustrate is that, although commercial funding may be a positive force in helping patient organizations establish themselves and make their voices heard, industry funding ultimately follows the commercial “mood” of companies and is strategically linked to their interests in expanding and protecting market shares [10]. This point was also illustrated in a U.S. Senator's report of six years of funding, from 2012 to 2017, awarded to pain groups by manufacturers of opioids [43]. The report showed that after Janssen sold U.S. licensing rights for its major opioid product line to Depomed in 2015, it terminated its funding of the pain groups, but the groups became increasingly funded by Depomed instead. More critically, these examples also illustrate how patient organizations that develop very close ties to companies may, justly or unjustly, have their independence questioned [26], especially in the context of high-profile pharmaceutical policy contentions such as those surrounding biosimilar switching [4] and opioid marketing [43].

Finally, we would suggest that patient organizations seriously consider whether it is defensible from the moral responsibility [44] and international solidarity perspectives to collaborate so closely with a company that, as was exposed in the recent U.S. Congressional investigation based on more than 170,000 pages of internal AbbVie documents [45], reportedly engaged in anti-competitive practices to block biosimilars from entering the U.S. market until 2023, while simultaneously hiking Humira prices. This has hindered many US patients' access to this essential medicine and is also depleting patient and public funds, while simultaneously reaping large gains for the company and its top management.

4.4. Study Limitations

Our study has several limitations. First, we relied on the information provided by companies to ENLI and had no possibility of independently verifying the data, including its completeness and veracity. In particular, we did not cross-check industry data with the records of industry funding that patient organizations are required by law to disclose on their websites, because the law stipulates that records be available for two years [22]. Second, the Danish data from before 2017 include only Danish Association of the Pharmaceutical Industry member companies, whereas subsequent years also include members of the Generic and Biosimilars Medicines Industry Association and the Danish Association for Parallel Importers of Medicines, but this is unlikely to have any major effect, since the absolute majority of payments are made by the large members of the Danish Association of the Pharmaceutical Industry. Third, there may be some companies that have chosen not to be trade group members or to abide by the industry's disclosure rules, although given the number of disclosing companies, this number is expected to be low [26]. Still, this means that we have probably underestimated the total funding. Finally, our study cannot demonstrate what effect, if any, particular funding had on patient organizations or companies, and we can only speculate about the motivations underlying the observed funding patterns [25].

5. Conclusion

This study used sector-wide pharmaceutical industry disclosure data to examine patterns of industry funding of patient organizations in Denmark over a six-year period, which was in the range of roughly €1–2 million per year. The year-over-year analysis was greatly facilitated by the Danish pharmaceutical industry's centralized disclosure mechanism which countries currently without centralized disclosures could adopt. The patterns in Denmark were broadly similar to what has been described for some other countries, for example, regarding the industry prioritizing support in commercially high-profile disease areas. However, the study also highlighted the arguably concerning dominance of one company in Denmark during a time of heavy policy contention

surrounding the world's top-selling medicine. Patient organizations have reasons to rethink some of their close collaboration with pharmaceutical companies, especially in the context of high-profile policy contentions nationally and internationally, and governments should ensure robust and equal funding across the patient group sector, including smaller organizations that may have more limited funding options.

Appendix

Supplemental Figure 1. Sunburst chart of industry funding by ICD-10 disease area (chapter) in Denmark (2014–2019)

Supplemental Figure 2. Sunburst chart of industry funding by ICD-10 disease area (chapter) in Sweden (2014–2019)

Supplemental Table 1. Year-over-year funding by AbbVie of the Hidradenitis Suppurativa, Autoimmune, and Parkinson's associations in Denmark

CRediT authorship contribution statement

Shai Mulinari: Conceptualization, Data curation, Formal analysis, Funding acquisition, Methodology, Writing – original draft, Writing – review & editing. **Dylan Pashley:** Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. **Piotr Ozieranski:** Conceptualization, Funding acquisition, Methodology, Writing – review & editing.

Declaration of Competing 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 a grant from Sigma Pharmaceuticals, a UK pharmacy wholesaler and distributor (not a pharmaceutical company).

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.healthpol.2022.11.003.

References

- Rose SL, Highland J, Karafa MT, et al. Patient advocacy organizations, industry funding, and conflicts of interest. *JAMA Intern Med* 2017;177(3):344–50.
- Lau E, Fabbri A, Mintzes B. How do health consumer organisations in Australia manage pharmaceutical industry sponsorship? A cross-sectional study. *Aust Health Rev* 2018;43(4):474–80.
- Ozieranski P, Rickard E, Mulinari S. Exposing drug industry funding of UK patient organisations. *BMJ* 2019;365:11806.
- Batt S, Butler J, Shannon O, et al. Pharmaceutical ethics and grassroots activism in the United States: A social history perspective. *J Bioethic Inq* 2020;17(1):49–60.
- Mintzes B. Should patient groups accept money from drug companies? *BMJ* 2007;334(7600):935.
- Moynihan R, Bero L. Toward a healthier patient voice: more independence, less industry funding. *JAMA Intern Med* 2017;177(3):350–1.
- Roennow A, Sauvé M, Welling J, et al. Collaboration between patient organisations and a clinical research sponsor in a rare disease condition: learnings from a community advisory board and best practice for future collaborations. *BMJ Open* 2020;10(12):e039473.
- Kent A. Should patient groups accept money from drug companies? *BMJ* 2007;334(7600):934.
- Fabbri A, Swandari S, Lau E, et al. Pharmaceutical industry funding of health consumer groups in Australia: A cross-sectional analysis. *Int J Health Serv* 2019;49(2):273–93.
- Mulinari S, Vilhelmsson A, Rickard E, et al. Five years of pharmaceutical industry funding of patient organisations in Sweden: Cross-sectional study of companies, patient organisations and drugs. *PLoS One* 2020;15(6):e0235021.
- Mandeville KL, Barker R, Packham A, et al. Financial interests of patient organisations contributing to technology assessment at England's National Institute for Health and Care Excellence: policy review. *BMJ* 2019;364:k5300.
- Kang SY, Bai G, Karas L, et al. Pharmaceutical industry support of US patient advocacy organizations: an international context. *Am J Public Health* 2019;109(4):559–61.
- Meyers DE, Meyers BS, Chisamore TM, et al. Trends in drug revenue among major pharmaceutical companies: a 2010–2019 cohort study. *Cancer* 2021;6. OctOnline ahead of print.
- Hemminki E, Toiviainen HK, Vuorenkoski L. Co-operation between patient organisations and the drug industry in Finland. *Soc Sci Med* 2010;70(8):1171–5.
- Colombo C, Mosconi P, Villani W, Garattini S. Patient organizations' funding from pharmaceutical companies: is disclosure clear, complete and accessible to the public? An Italian survey. *PLoS One* 2012;7(5):e34974.
- Moriarty F, Larkin J, Fahey T. Payments reported by the pharmaceutical industry in Ireland from 2015 to 2019: An observational study. *Health Policy* 2021;125(10):1297–304.
- Ozieranski P, Martinon L, Jachiet PA, Mulinari S. Tip of the iceberg? Country-and company-level analysis of drug company payments for research and development in Europe. *Int J Health Policy Manage* 2022. 10.34172/ijhpm.2022.6575.
- Keizer B, Bless R. Pilot study on the position of health consumer -patients' organizations in seven EU countries. The Hague: ZonMW; 2010.
- Rabeharisoa V. Patient organizations and the economic and industrial world - towards new types of relationship? In: Akrich M, Nunes J, Rabeharisoa V, Paterson F, editors. The dynamics of patient organizations in Europe. Paris: Presses des Mines; 2008. p. 83–142.
- Mulinari S, Martinon L, Jachiet PA, et al. Pharmaceutical industry self-regulation and non-transparency: country and company level analysis of payments to healthcare professionals in seven European countries. *Health Policy* 2021;125(7):915–22.
- Opedal S, Rommetvedt H, Vrangbæk K. Organised interests, authority structures and political influence: Danish and Norwegian patient groups compared. *Scand Politic Stud* 2012;35(1):1–21.
- Danske Patienter. 2020. Patient-, pårørende- og handicapforeninger i Danmark. Copenhagen: Danske Patienter. https://danskepatienter.dk/sites/danskepatienter.dk/files/media/Publikationer%20-%20Egne/A_Danske%20Patienter/B_Indspil_cas_ses_undersogelser/foreninger-i-danmark.pdf Accessed July 29, 2022.
- Pashley D, Ozieranski P, Mulinari S. Disclosure of Pharmaceutical Industry Funding of Patient Organisations in Nordic Countries: Can Industry Self-Regulation Deliver on its Transparency Promise? *Int J Health Serv* 2022;52(3):347–62.
- R Core Team. 2017. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. <http://www.R-project.org/>.
- Parker L, Fabbri A, Grundy Q, et al. Asset exchange"—interactions between patient groups and pharmaceutical industry: Australian qualitative study. *BMJ* 2019;367:l6694.
- Ozieranski P, Pitter JG, Rickard E, et al. A 'patient–industry complex'? Investigating the financial dependency of UK patient organisations on drug company funding. *Sociol Health Illn* 2022;44(1):188–210.
- EFPIA. 2011. EFPIA Code of Practice on relationships between the pharmaceutical industry and Patient Organisations. https://www.efpia.eu/media/24310/3c_efpia-code-of-practice-on-relationships-pharmapluspt-orgs.pdf Accessed October 13, 2021.
- ENLI. 2015. Ethical Rules for Collaboration between Patient Organisations, etc., and the Pharmaceutical Industry. <https://www.enli.dk/media/38995/Ethical-Rule-s-for-Collaboration-between-Patient-Groups-april-2015.pdf> Accessed October 13, 2021.
- Danske Patienter. 2018. Retningslinjer for medlemsforeningernes samarbejde med medicinal- og medicoindustrien. <https://danskepatienter.dk/sites/danskepatienter.dk/files/media/document/Retningslinjer%20for%20samarbejde%20med%20industrien%202022.pdf> Accessed July 29, 2022.
- Coghlan J, He H, Schwendeman AS. Overview of Humira® biosimilars: current European landscape and future implications. *J Pharm Sci* 2021;110(4):1572–82.
- ENLI. 2022. Samarbejder med patientforeninger – Reports 2020 and 2021. <https://www.enli.dk/samarbejder-med-patientforeninger/> Accessed July 29, 2022.
- Miller I, Lynggaard C, Lophaven S, et al. A double-blind placebo-controlled randomized trial of adalimumab in the treatment of hidradenitis suppurativa. *Br J Dermatol* 2011;165(2):391–8.
- Kimball AB, Kerdel F, Adams D, et al. Adalimumab for the treatment of moderate to severe hidradenitis suppurativa: a parallel randomized trial. *Ann Intern Med* 2012;157(12):846–55.
- Kimball AB, Okun MM, Williams DA, et al. Two Phase 3 trials of adalimumab for Hidradenitis Suppurativa. *N Engl J Med* 2016;375(5):422–34.
- Prescrire. A public awareness campaign which mainly benefits companies. *Prescrire Int* 2020;29(219):250.
- Grant K. How pharma companies try to use funding to sway patient advocate groups. *The Globe and Mail* 2018. October 21, <https://www.theglobeandmail.com/canada/article-how-pharma-companies-try-to-use-funding-to-sway-patient-advocate/Accessed>. October 13, 2021.
- Kopp, E., Lupkin, S., and E. Lucas. 2018. Patient advocacy groups take in millions from drugmakers. Is there a payback? *The Washington Post*, April 06. https://www.washingtonpost.com/gdpr-consent/?next_url=https%3a%2f%2fwww.washingtonpost.com%2fnational%2fhealth-science%2fpatient-advocacy-groups-

- take-in-millions-from-drugmakers-is-there-a-payback%2f2018%2f04%2f06%2f0a75f988-397b-11e8-af3c-2123715f78df_story.html Accessed October 13, 2021.
- [38] European Medicines Agency. 2017. Biosimilars in the EU: information guide for healthcare professionals. https://www.ema.europa.eu/en/documents/leaflet/biosimilars-eu-information-guide-healthcare-professionals_en.pdf Accessed October 13, 2021.
- [39] Colitis-Crohn Foreningen, Foreningen for Unge med Gigt (FNUG), Gigtforeningen for Morbus Bechterew et al. 2016. Seminar om biosimilære lægemidler: same same but different? Available at: <https://psoriasis.dk/nyheder/seminar-om-biosimilære-lægemidler-same-same-but-different> Accessed October 13, 2021.
- [40] Nielsen C, Villumsen B, Tryde J, et al. Bøn fra patientforeninger: Giv patienterne reel indflydelse ved medicinskift. *Dagens Medicin* 2018;28. October, <https://dagensmedicin.dk/boen-fra-patientforeninger-giv-patienterne-reel-indflydelse-ved-medicskift/> Accessed. October 13, 2021.
- [41] Jensen TB, Kim SC, Jimenez-Solem E, et al. Shift from adalimumab originator to biosimilars in Denmark. *JAMA Intern Med* 2020;180(6):902–3.
- [42] Taylor, N. 2021. AbbVie's Parkinson's pump hits goal in phase 3, setting stage for approval filings. Fierce Pharma. <https://www.fiercepharma.com/drug-delivery/abbvie-s-parkinson-s-pump-hits-goal-phase-3-setting-stage-for-approval-filings> Accessed July 29, 2022.
- [43] McCaskill, CC. 2018. Fueling an epidemic: Report Two. Exposing the financial ties between opioid manufacturers and third party advocacy groups. Washington D.C.: US Senate Homeland Security & Government Affairs Committee., <https://www.hsgac.senate.gov/imo/media/doc/REPORT-Fueling%20an%20Epidemic-Exposing%20the%20Financial%20Ties%20Between%20Opioid%20Manufacturers%20and%20Third%20Party%20Advocacy%20Groups.pdf> Accessed July 29, 2022.
- [44] Müller R, Rach C, Salloch S. Collective forward-looking responsibility of patient advocacy organizations: conceptual and ethical analysis. *BMC Med Ethic* 2021;22(1):1–11.
- [45] Drug Pricing Investigation AbbVie—Humira and Imbruvica. Committee on Oversight and Reform U.S. House of Representatives.; 2021. Accessed October 13, 2021. <https://oversight.house.gov/sites/democrats.oversight.house.gov/files/Committee%20on%20Oversight%20and%20Reform%20-%20AbbVie%20Staff%20Report.pdf>