Should patient groups be more transparent about their funding?

Patient groups often shout loudly for access to drugs but are quieter about their links to industry. Sophie Arie and Chris Mahony ask whether this is acceptable given increasing demands for transparency elsewhere in medicine.

The recent decision that the multiple sclerosis drug nabiximols should be available on the NHS in Wales was met by MS charities as a small triumph for patients. Access to the drug, a cannabinoid spray that eases spasticity, had previously been denied because of its cost. “As a charity we have campaigned over a long period for Sativex [nabiximols] to be widely available because of the significant impact that MS spasticity can have on daily activities,” Amy Bowen, director of service development at the Multiple Sclerosis Trust, told the BBC.1

She expressed hope that the recommendation would lead to the drug being more easily accessible in the rest of the UK.

The MS Trust failed, however, to mention either in media interviews or in lobbying documents, that it receives funding from the German drug giant Bayer, which markets the drug in the UK. The company donated £5000 (£6400; $8200) to the MS Trust in 2013 and 2012.2 1

On its website, the charity provides information about its corporate funding only in its annual review, and even this is not prominently displayed. Corporate funding is listed as a lump sum of £54 121 towards the back of the annual review, without naming individual companies or specifying how the funds were used. There is one reference within further tables of figures to a restricted grant from Sanofi.3

The Association of the British Pharmaceutical Industry requires drug companies to disclose all the details of their relations with patient groups and charities systematically and prominently on their websites. These show that, in addition to the £5000 from Bayer, the MS Trust has received significant sums in recent years from several other producers of MS drugs, including £15 000 from Genzyme, a Sanofi company which makes teriflunomide and over £50 000 from Biogen Idec, which makes interferon beta 1a, fampridine, and dimethyl fumarate and has several more MS treatments in development.4

The MS Trust did not respond when asked whether greater transparency would be better, but it said in a statement that the charity’s independence and integrity was protected by its policy on working with the drug industry, which is on its website.4

“At the MS Trust we believe that if a drug has been assessed as safe and effective and given a licence, we should do our utmost to ensure it is accessible to all who might benefit. We do this for all licensed MS drugs, regardless of the manufacturer,” the statement said.

In June this year, the head of the MS Society, Michelle Mitchell, wrote a letter in the Daily Telegraph, co-signed by several MS experts,7 criticising the National Institute for Health and Care Excellence (NICE) for blocking access to the “life-changing” drugs nabiximols and fampridine even though “they are licensed and proven to be effective at helping people walk more easily and control painful muscle spasms.” Yet the letter did not mention that the MS Society had received money from the companies who make and market those drugs (box).

The case of the MS charities is only a recent example of what could be perceived as an almost universal conflict of interest for patient groups. Nearly all such groups receive funding from drug companies and most are, by definition, the greatest champions of the products those companies sell. But the amount of information, and the prominence it is given on charities’ websites, varies enormously. Some charities have clear and comprehensive information about funding on the primary pages of their websites. Many provide only partial information, often recorded in areas of their annual reports which may be hard to find.

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**COMPETING INTERESTS**

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**MS SOCIETY AND DRUG COMPANY FUNDING**

The MS Society received over £21 000 from Biogen Idec, £46 000 from Genzyme, and £5000 from Bayer in 2013. The charity names its corporate donors on the “corporate supporters” page of its website, but to find the sums involved you have to look at the last element of the annual accounts on page 50 of its 54 page annual review.7

“We know this is a sensitive issue and that we have to draw the balance between receiving money that enables us to achieve our charitable aims and ensuring that we maintain our independence,” said Nick Rijke, executive director of policy and research at the MS Society. “We’re very careful and are confident we have the balance right. We keep the amounts low and we publish them precisely to ensure that there is no risk of being compromised.”

The society’s policy on working with drug companies states that no more than 5% of its income in any one year can come from these sources and, the charity says, in 2013 0.6% of its income came from them.10
So does it matter if charities fail to mention their corporate donors when campaigning in favour of the drugs they make?

Questions over independence

Drug companies are a key source of funding for many patient groups, and the companies say that their financial support for charities is a logical “partnership” between those with a common interest in improving treatment and care for patients. Most charities campaign for access to newly licensed drugs for their patients and would do so with or without corporate funding, on the basis that their patients deserve to benefit from all licensed drugs for their condition. Most consider the issue to be resolved by policies on working with industry that include a limit on the proportion of total income to be received from corporate donors and avoiding donations from only one company.

Yet, there is growing concern that charities, like any other sector, should be more transparent about their funding given that they are widely perceived by patients, the public, and policy makers to be independent.

“If they are not open about the fact they receive money from drug companies then how can you evaluate the quality of their advice?”

Angela Coulter

“Being aware of any financial relationship with the sponsor provides context for the advisory committee’s consideration of the views being put forward”

Andrew Dillon

“Any time any organisation takes money from anybody for any purpose there is potential for a conflict of interest”

Jeremy Taylor

“Marketing in research’s clothing can pass charities by without them realising”

Paul Wicks

In the case of a regulatory body such as NICE, the experts drawing up guidelines are aware of the financial ties of patient representatives to the companies whose drugs are being assessed. Patient experts giving advice to advisory committees declare any conflicts of interests at the committee meetings, but their input is considered to be unacceptable only if they have personally received a payment that relates to a drug or treatment under review. If they are an employee of a patient organisation that receives funds from a drug company, their advice may still be taken into account.

“Being aware of any financial relationship with the sponsor provides context for the advisory committee’s consideration of the information and views being put forward by the expert” NICE’s chief executive Andrew Dillon told The BMJ.

“Almost all patient groups have some sort of funding from the companies involved in that disease, so to refuse input to anyone taking this funding would preclude them all,” says Ken Paterson a former head of the Scottish Medicines Consortium, the Scottish equivalent of NICE.

“Any time any organisation takes money from anybody for any purpose there is potential for a conflict of interest”

Jeremy Taylor

Patient experts giving advice to advisory committees should be independent, he says. “Politicians and the wider public believe them to be totally independent,” he says. “Politicians and the wider society need to be aware that they [patient groups] may not be entirely unbiased when they protest at decision over drug funding. There may be some levels of subliminal influence. This is why any money changing hands should be transparent.”

Overstepping

There have only been a few reported cases of charities’ activities being clearly compromised by their relationships with a drug company and there is no reason to suspect that this is widespread. But the cases that have come to light have fuelled concern over a need for a culture of full disclosure.
The charity has decided not to use the data from the survey. However, it continues to take funding from AbbVie, and other drug companies sponsor activities such as educational programmes for doctors and nurses and awareness campaigns for politicians and the general public, she said. She did not say whether this sponsorship is made clear to those targeted but did state that the charity follows the ethical guidelines and recommendations of the Swedish industry trade body LIF and publishes full details of donations it receives on the LIF website.

“There have been implications for the drug company but nothing has happened to the charity,” Riggarre told The BMJ.

Ensuring transparency

Opinions are divided among health charities between those who are adamant their donors wield no influence and those who believe that charities need to be more transparent about their relationships with industry to preserve their reputations. Some, such as the mental health charity MIND, go so far as refusing any support from industry.

MIND’s fundraising director, Cathleen Miles, says: “Only by remaining totally independent of pharmaceutical companies can we retain that voice of independence and provide objective information to anyone who comes to us for support in making decisions about what treatment is best for them.”

Others believe that clearer guidelines are needed for all health charities to adhere to. But getting such a broad group of charities, which work to different national regulations from country to country, to agree on common rules on transparency could be difficult. There is also concern that federations of patient groups—both national and international—receive funding from industry that is not clearly labelled in individual groups’ accounts because it is channelled through the umbrella group.

Under regulations established by the Charity Commission, charities in the UK are not legally required to name all their donors. A spokesperson for the Charity Commission explained that “the legal requirements set a standard that charities must follow but they can, and many do, go over and above the legal expectations. We encourage charities to be transparent. We expect that trustees are diligent in this duty to protect the independence and the reputation of their charity.”

Drug companies in the UK generally adhere to the ABPI’s code of practice, which is overseen by the Prescription Medicines Code of Practice Authority (PMCPA). When a company is found to be at fault, it might be required to issue a corrective statement or publish an advertisement. Obviously the authority cannot discipline a patient group.

Taylor says National Voices has recently begun working with the ABPI to produce a joint guide to explain the code and set down some principles for growing the relationship between that industry and partners. The guide could cover the importance of governance, protecting independence, transparency, income diversity, and what to think about when entering an arrangement with a drug company.

“We are hoping it can be an equivalent to the joint ABPI-Department of Health guidance on collaboration between pharma and NHS organisations,” he says. “It is helpful for us to be crystal clear about how much money an organisation receives from whom to do what, but that is not enough. The process of governance and internal scrutiny and discussion are as important. The code itself seems to involve a lot of red tape for the company with various forms—none of which seem to get to the heart of ethics and governance of relationships.”

At an international level, the International Alliance of Patients’ Organisations (IAPO) acknowledges there is a problem.

“We aspire to be as transparent as possible. Different people have a different understanding of what that means,” Jo Groves, the organisation’s chief executive says. “The pharmaceutical industry have got there through a process and patient groups need to do that too.”

But IAPO can only advise its members on best practice; it cannot force them to comply or impose any sanctions if they don’t.

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A survey funded by AbbVie about the drug Duodopa was sent to members of the Swedish Parkinson's Disease Association. But no mention was made of a corporate sponsor.