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THE CONVERSATION

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Do consumer groups really advocate for the public interest?

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The Guardian [recently claimed](#) to have exposed an attempt by a number of pharmaceutical companies to thwart efforts by the European drug regulator (the European Medicines Agency) to have all clinical trial data made available to the public.

The tactic is apparently being used by industry, and coordinated by the [Pharmaceutical Research and Manufacturers of America](#) (PhRMA) and the [European Federation of Pharmaceutical Industries and Associations](#) (EFPIA).

The idea is to mobilise patient advocacy groups to campaign against greater transparency on the grounds that information might be misinterpreted and cause health scares. Several companies have denied using such a strategy, while others have refused to comment.

Public health and transparency

Whether or not such a campaign has indeed been launched by the pharmaceutical industry, the article highlights two important issues about contemporary drug development, regulation and public health.

The first is whether greater transparency on the part of the pharmaceutical industry is necessarily in the public interest. The second is whether so-called public advocacy groups actually serve the interests of the consumers they supposedly represent, and whether they serve an important public function.

With respect to transparency, some argue that information that is not presented accurately or contextualised properly could both undermine commercial drug development and lead to unfounded fears about medicines and vaccines.

Others counter that such claims are unfounded, that misunderstandings happen anyway, and that mechanisms can be put in place to manage the impacts of disclosure.

It's difficult to argue against the latter position.

Transparency is [not the moral panacea](#) it's sometimes claimed to be; it can, in some circumstances, lead to worse behaviour on the part of those being observed. And it may engender misplaced trust that equates greater openness with good behaviour.

But we cannot see any reason in this situation to hide the results of clinical trials, particularly when members of the public have placed themselves at risk by participating in the trials.

Hidden interests

So, what do the people speaking out against it really think of transparency, and why do they hold the view that it could be harmful? Do groups criticising moves toward regulatory transparency really want thousands of [clinical trials to remain unreported](#), or are they being manipulated to say so by the pharmaceutical companies that fund them?

This is ultimately an empirical question that cannot be answered here, but it does raise the broader issue of the whether or not health-related public advocacy groups — many [funded by industry](#) — actually represent the interests of patients.

There's no doubt that, in some circumstances, patient organisations have successfully advocated for positive change in the development, regulation, funding, and quality use of medicines.

Consumers and patient advocacy groups are increasingly interested in ensuring that the research agenda generates the products and clinical outcomes that matter to them. And, in some areas, such as [HIV](#) and [multiple myeloma](#), this has had a significant effect on the research agenda.

Consumer groups have also advocated for changes to medicines regulation, including of [complementary medicines](#), for government funding of new medicines, such as [Herceptin for breast cancer](#), and for [greater patient involvement](#) in clinical decision-making.

Patients may have benefited from the work of consumer advocates, but they are not only ones.

While consumers are sometimes [critical of the pharmaceutical industry](#), in most cases, consumer involvement in the development, regulation and funding of medicines has led to earlier and more extensive access to medicines, which benefits industry as well as patients.

Two-way street

The pharmaceutical industry is not blind to the power of the consumer, which is why so many patient advocacy groups are supported by industry. And why such relationships are explicitly [supported by Medicines Australia](#) (the pharmaceutical industry's peak body in Australia).

Consumer groups are not the only targets of industry, which also funds direct-to-consumer advertising, expert advisory committees, researchers, clinicians and policymakers.

Indeed, consumer groups are really just one part of a targeted network of industry influence that impacts on every aspect of drug development, regulation, resource allocation and clinical practice.

While there may be nothing wrong as such with synergies between commercial and public interests, it shouldn't be forgotten that consumer campaigns have their costs, whether to research (HIV clinical trials were stopped early to allow patients to access experimental medicines, for instance) or to the public purse (Herceptin was deemed to not be cost-effective by the Pharmaceutical Benefits Advisory Committee, but is now [funded by a special government program](#)).

Clearly, there are [opportunity costs](#) associated with such consumer-led interventions and they can be significant.

So it's in the public interest to establish the degree of consumer groups' independence and to expect that their relationships with industry are both disclosed and appropriately managed.

Medicines Australia's Code of Conduct, and its [formal collaboration](#) with the Consumers Health Forum of Australia and other health consumer organisations, might provide some leverage in this regard.

These organisations explicitly [espouse the principles](#) of “respect for independence”, “fairness”, “openness and transparency” and “accountability” as the basis for industry-consumer interactions.

As long as we collectively endorse – implicitly or explicitly – direct interactions between pharmaceutical companies and consumer groups, these are the criteria against which consumer groups (as well as the companies that support them) should be judged.