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Considerations when conducting research with representatives from industry-funded health consumer groups: insights from an Australian national survey

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Abstract

Background and Aims: Health consumer representatives, individually or as part of Consumer Advisory Groups, play a crucial role in pharmacoepidemiology and other research on medicines and devices, drawing attention to the experiences, priorities, and needs of intended beneficiaries. It is not uncommon for these representatives to be drawn from consumer groups that have formed to provide support and advocacy for specific health conditions. Pharmaceutical and device industry financing of such groups is widespread however and creates a conflict of interest between a group's mandate to represent members' interests and sponsors' priorities. At stake is health advocacy policy that reflects both over- and under-representation of selected patient interests. For example, representatives of industry-financed groups may have difficulty advocating for a primary focus on product safety or on non-drug treatments. Clear guidance on how consumer groups can best address conflicts of interest that arise from partnerships with industry to avoid undue influence is lacking.

Design and Methods: From May to June 2026, we are conducting a national online survey of Australian consumer groups to assess their interactions with pharmaceutical and device companies and to understand the tools and practices groups use to manage relationships with these companies. The survey covers three key areas of consumer group activity: education, advocacy, and research. The current analysis focuses on research governance.

Results: Survey results will map companies' involvement in consumer group research activities and participation of groups' representatives in industry-led research; groups' policies and management practices; perceptions of influence and pressure to align with company interests; and perceived impact of existing management tools and strategies in controlling potential influence. These findings will inform a practical toolkit of resources such as policy and contract templates, and disclosure standards that consumer groups can use to better navigate research partnerships and sponsorship arrangements with companies.

Conclusions: This first national survey of consumer groups' management of conflicts of interest arising from industry funding and subsequent development of a practical toolkit may assist researchers who are recruiting and involving consumer representatives from industry-funded consumer organisations, to mitigate risks of undue influence and enable full representation of consumer interests.