

WORKING TOGETHER

REVISED EDITION

THE GUIDE

A Guide to relationships between
Health Consumer Organisations
and Pharmaceutical Companies

WORKING TOGETHER

When health consumers and stakeholders work collaboratively, great outcomes can be achieved. In 2005, the Consumers Health Forum of Australia and Medicines Australia collaborated to develop the *Working Together Guide*, and in 2008 both organisations undertook a review to ensure the document remains relevant, informative and functional.

The original Guide recognised the increasing number of relationships between health consumer organisations and the pharmaceutical industry, and the need to assist both parties to work together appropriately in a transparent and accountable way. The framework of the Guide concentrated on guiding principles and good examples of joint partnerships.

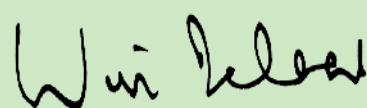
This 2008 review builds on these experiences and provides valuable and practical information for health consumer organisations and pharmaceutical companies that are considering entering into a working relationship.

Both Guides were based on consultation with both health consumer organisations and pharmaceutical companies and we would like to thank those individuals and organisations who provided input to the development of the original Guide and the review process. In particular, we thank the Steering Committee, who spent a great deal of time ensuring the Guide meets the needs of all stakeholders.

We are proud of the Guide and the consultative process that led to its development. We commend it to you as an excellent starting place for health consumer organisations and pharmaceutical companies to use when working together.



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Chairperson
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Why this guide?

Health consumer organisations and pharmaceutical companies have collaborated for many years to address the needs of health consumers.

The number and complexity of these relationships is increasing, and both pharmaceutical companies and health consumer organisations are increasingly looking for advice on how to work together successfully.

To assist the development of these relationships, the Consumers Health Forum of Australia and Medicines Australia have developed this Guide. The Guide provides a starting point for potential relationships to be established. It offers some basic principles and suggestions which individual organisations can adapt to their own needs. Separate, more detailed supporting materials, "*Working Together, The Manual*", have been produced to assist those who may need further support or information. The Manual is attached to this Guide in hardcopy and is available at www.chf.org.au or www.medicinesaustralia.com.au

Structured collaborations are not suitable for every organisation or project but, done well, they can deliver great results for health consumer organisations, the pharmaceutical industry and, most importantly, the Australian community.

Who is working together?

Health consumer organisations are not-for-profit organisations that represent the interests and views of consumers of health care. They may range from small volunteer groups to large organisations, and generally promote views that are independent of government, the pharmaceutical industry and professional health service providers

When setting out to work with health consumer organisations, pharmaceutical companies need to be aware that:

- health consumer organisations vary greatly in their expertise and resources
- there may be several health consumer organisations dealing with the one disease or condition
- some health consumer organisations have both state and national offices, and the people and resources involved from a health consumer organisation may be located in different parts of Australia.

Pharmaceutical companies are businesses that discover, develop, manufacture and market medicines. Like health consumer organisations, pharmaceutical companies are committed to improving and maintaining good health in all Australians.

Health consumer organisations need to be aware, when approaching pharmaceutical companies, that most companies have several departments that deal with health consumer organisations. These departments may include:

- marketing and sales (product managers and sales representatives)
- corporate affairs (relationship managers including consumer and community relations)
- medical department (including clinical researchers, medical information, medical advisers, doctors, pharmacists and health economists).

These departments may have different objectives, ways of thinking about health and medicines and ways of participating in relationships.

Types of relationships and ways of working together

Relationships between health consumer organisations and pharmaceutical companies may include:

- one-off projects
- longer-term relationships.

Organisations participating in one-off projects usually limit their contributions to the specific needs of that project.

One-off projects often involve a donation, sponsorship or an untied educational grant by a pharmaceutical company to a health consumer organisation to undertake specific activities. This can involve a limited return to the pharmaceutical company beyond an agreed acknowledgement process, such as in the health consumer organisation's annual report.

Longer term relationships often take the form of 'collaborations', which involve the pharmaceutical industry and health consumer organisation working together on issues of common interest. Both make contributions of some kind, which can involve funds, sharing of information, education and training, as well as other support, and both derive benefits from their work together. They collaborate to achieve goals that they otherwise could not reach alone.

Collaborative relationships usually involve contributing time, people and resources to support the relationship, above and beyond the needs of specific projects. Although longer-term relationships may involve greater resources for both pharmaceutical companies and health consumer organisations, they can also deliver deeper understanding, greater certainty and better outcomes for both parties.

Collaborations may involve more than one health consumer organisation or pharmaceutical company.

Some benefits of working together

Health consumer organisations and pharmaceutical companies often work together to improve the health and quality of life of consumers.

They may collaborate for other or more specific reasons as well. Relationships between health consumer organisations and pharmaceutical companies work better if each party is open and clear about what it wants to achieve by working together.

Opportunities for both health consumer organisations and pharmaceutical companies include:

- development of and access to information and education resources
- generating greater awareness of health conditions and related issues
- skills sharing
- greater understanding of consumers' needs
- a broader understanding of health and treatment options
- greater understanding of the other party
- timely access to new medicines and treatments.

Potential benefits to health consumer organisations include:

- developing information and education resources
- gaining access to information, scientific data, advice and equipment relevant to consumers
- accessing key opinion leaders in therapeutic areas
- attending conferences/workshops and other professional development opportunities
- securing funding and other resources
- increased public awareness and understanding of the health consumer organisation's role
- building understanding of options for managing health conditions.

Potential benefits to pharmaceutical companies include:

- opportunities to learn about consumers' needs and experiences
- increased understanding within health consumer organisations of bringing a medicine to market
- increased understanding within health consumer organisations of the value of medicines
- engagement with consumer networks
- opportunities to provide information about managing health conditions
- securing support when applying for Pharmaceutical Benefits Scheme listing of medicines
- appropriate use of medicines
- enhanced company awareness, sales and reputation.

Benefits may extend beyond the life of the relationship and may result in building overall capacity of both the health consumer organisation and pharmaceutical company.

Important principles of working together

Relationships between health consumer organisations and pharmaceutical companies should involve the following components that are essential in any relationship:

- honesty
- integrity
- trust
- respect

There are also other important principles more specific to health consumer organisations and pharmaceutical company relationships. Because pharmaceutical companies and health consumer organisations are very different types of organisations, it is wise to discuss these in detail before beginning any project or relationship.

Respect for independence

Effective working relationships bring two (or more) independent parties with different skills together for a common purpose. Each party remains true to its purpose and expresses its views accordingly, even where the other party doesn't agree. Neither party should compromise the integrity or independence of the other.

Achieving and maintaining public trust

A relationship that appears to have compromised the independence or integrity of one or both of the parties is of little value. The relationship's full potential is only realised when the community trusts that the intent of the relationship is to deliver better health outcomes for the community. Therefore, health consumer organisations and pharmaceutical companies need to consider how to avoid any perception that one party has unfairly influenced or compromised the other.

Fairness

Pharmaceutical companies and health consumer organisations will differ greatly in what they bring to a relationship. Although each party may have very different strengths, when negotiating the relationship or when acting within it, both should feel free to raise issues, speak openly and not feel pressured by the other. Fairness applies at the beginning, throughout, and at the end of a relationship. Fair and appropriate exit strategies should be part of any agreement to work together.

Openness and transparency

Relationships benefit if both parties are clear and honest about what each hopes to achieve from the relationship. This includes being clear about roles and responsibilities, being open about the constraints under which each party is operating, and through each party disclosing any other relevant collaborations in which it is involved.

It is important to agree at the outset how each party will be acknowledged throughout the collaboration. Acknowledgement can take many forms including in materials produced or within a web site or an annual report.

If a goal of the relationship is to produce tangible products, for example, educational resources, it is essential to agree on the ownership of the resources or information. Health consumer organisations and pharmaceutical companies need to agree on who will own the Intellectual Property of the resources.

Openness between the parties is also consistent with respect for confidentiality and privacy within the relationship. One benefit of collaborating is that pharmaceutical companies and health consumer organisations can gain access to scientific data and other information that is not publicly available. Some of this may be commercially valuable or politically sensitive and can be privileged information. All parties need to agree on what information can and cannot be used for, the terms under which information will be shared, and how security and privacy will be maintained.

Accountability

Parties should work out how they will be accountable to each other – how they will show that the resources contributed by each have been used appropriately, and agreed outcomes achieved.

The health sector has many stakeholders: the parties themselves, governments, current and potential users of medicines, shareholders and, indirectly, all Australian health consumers. All of these groups have a stake in the relationship's success. Parties may like to think about the ways in which they can report back to these stakeholders on the results of their relationships.

Accountability requires effort, so some time should be spent working out how support will be provided by each organisation to achieve this.

Setting outcomes

It is important to identify the expected outcomes from the beginning of the relationship and to check they have been achieved at the end. For longer term relationships, it is often appropriate to hold regular reviews to ensure that each organisation's objectives are still being met and to discuss any necessary changes.

Some outcomes will be easy to quantify, for example:

- educational resources produced and distributed
- enhanced consumer access to medicines
- increase in disease awareness
- improved and appropriate use of medicines
- conferences attended.

Some outcomes may be far less tangible, for example:

- knowledge and skills gained
- access gained to services or expertise
- links with key decision-makers established.

Very often, pharmaceutical companies and health consumer organisations will get quite different benefits and seek different outcomes from the relationship.

A checklist of things to think about

Because each relationship between a health consumer organisation and a pharmaceutical company will be different, the same approach may not work for all of them.

The following checklist highlights questions that are often important in health consumer organisation and pharmaceutical industry relationships. Health consumer organisations and pharmaceutical companies will need to adapt these to their particular circumstances.

Deciding to collaborate

- what are our goals?
- what are the goals of our potential partner?
- what objectives do we have in common?
- what will we each do to achieve agreed objectives?
- is this relationship consistent with our overall organisational goals?
- what other related projects/relationships may impact on this relationship?
- will any funding arrangement be perceived as appropriate?
- who will own the products of the relationship?
- how will we ensure Intellectual Property is protected?
- how will we measure the results of the relationship?
- have we considered the sustainability of the project?

Questions for health consumer organisations in particular:

- what will we do to ensure our independence?
- what is the best department of the pharmaceutical company to work with?
- what sort of acknowledgement or endorsement does the pharmaceutical company expect?
- do we have the required resources to achieve the goals of the relationship?
- have we considered the benefits and risks of the type of funding or sponsorship involved?
- if the funding for the relationship ceases what impact will it have on the sustainability of the organisation?

Questions for pharmaceutical companies in particular:

- does the health consumer organisation represent the areas that are important to this company, its goals and its products?
- does the health consumer organisation have the people, resources and capacity to achieve the relationship goals?
- what is the health consumer organisation's decision-making process, and how long will it normally take to formalise decisions?

Formalising the agreement

- how will we record our agreement? (for example, a contract, a memorandum of understanding, an exchange of letters, an invoice or a verbal agreement)
- who will have the authority to make decisions for each organisation?
- have we agreed on a process for conflict resolution?
- have we agreed on an evaluation methodology?

Making the relationship work

- how will we support the relationship/project?
- what will we need to contribute? (for example, time, people, funds, information, resources)
- what do we want the other party to contribute?
- what, if anything else, do they expect from us?
- who will be the main points of contact in each organisation?
- what is the overall timetable of activities?
- how will contributions be acknowledged?
- how will confidential and private information be kept secure?
- have we agreed what information will be private and what will be public?
- how will we keep stakeholders, including our members, informed of our work?
- how will we evaluate the success of the partnership?
- how will Intellectual Property be acknowledged?

Concluding the relationship

- how long is the relationship intended to last?
- how will we check our objectives have been met?
- if we need to conclude early how will the relationship be managed?
- if there are ongoing activities how will these be managed?

Evaluating outcomes of the relationship

- were the goals achieved?
- were we treated fairly?
- was the investment of time, resources and people worthwhile?
- if the opportunity arose would we be willing to work together again?

More Information

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web: www.medicinesaustralia.com.au

Relevant resources

Medicines Australia Code of Conduct

Medicines Australia Code of Conduct sets out standards of conduct for the activities of companies when engaged in the marketing of prescription products used under medical supervision as permitted by Australian legislation.

www.medicinesaustralia.com.au/

Consumers Health Forum of Australia guidelines for health consumer organisations receiving pharmaceutical funding for consumer education

These guidelines were developed in 2001 and relate specifically to funding for consumer education.

www.chf.org.au/Docs/Downloads/270_pharmfund.pdf

Electronic copies of this Guide and the Manual are available on both Consumers Health Forum of Australia's and Medicines Australia's websites.

www.chf.org.au

www.medicinesaustralia.com.au

Original project Steering Committee 2004-05:

Gillian Adamson (Pfizer Australia); Andrew Alexandra (Centre for Applied Philosophy and Public Ethics, University of Melbourne); Melanie Cantwell (Consumers Health Forum of Australia); Russell Edwards (Amgen Australia Pty Ltd); Judith Griffin (Merck Sharp & Dohme Australia Pty Ltd); Elke Purnell (Medicines Australia); Sheila Rimmer AM (Consumer Representative); Janney Wale (Consumer Representative); Mary Wooldridge (Foundation for Young Australians).

The follow-up Review was conducted in 2008, Steering Committee members included:

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Sue Cunningham of RPR Consulting conducted the review of the Guide and Manual and wrote the new material in this revised Guide.

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