



Working Together

A guide to relationships between health consumer
organisations & pharmaceutical companies

Foreword

Welcome to the fourth edition of the Working Together Guide. This Guide was developed by Consumers Health Forum (CHF) and Medicines Australia.

This guide is written for pharmaceutical companies and Health Consumer Organisations (HCOs)- which play a vital role in representing and advocating for patients across the healthcare system. While the direct audience for this Guide is HCOs, we recognise that these organisations work closely with-and on behalf of- the people we all ultimately serve- patients. Strengthening collaboration between pharmaceutical companies and HCOs is one of the most effective ways, we can support better health outcomes for individuals, carers, families and communities across Australia.

Consumers Health Forum (CHF) is the national peak body representing health consumers. CHF work to make sure healthcare in Australia is accessible, affordable and safe. They are the independent 'voice' of health consumers, and amplify their views, and advocate for their needs. CHF believe in "nothing about us, without us".

Medicines Australia represents the research-based pharmaceutical industry of Australia. Its members discover, develop and manufacture the medicines and vaccines that are the foundation of a healthy and prosperous society.

This Guide reflects our shared commitment to strengthening partnerships, that are grounded by mutual respect, transparency and a clear focus on the needs of patients. Since the last edition in 2015, the way we think about healthcare has changed. More than ever, there's recognition that patients are not just recipients of healthcare, they are experts in their own health. Their insights, experiences and voices are essential and should be included at every stage of the medicine journey from research and development to approval, access and delivery.

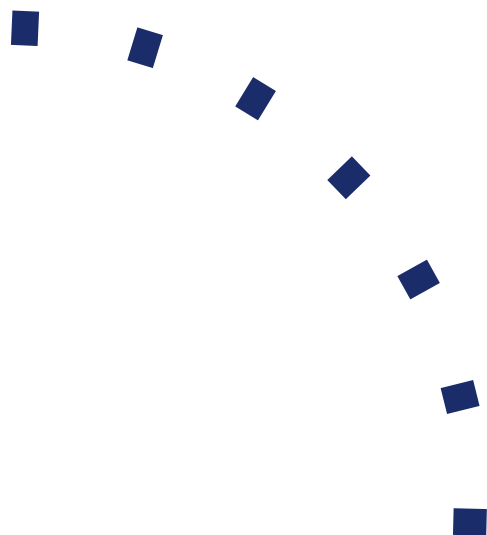
When we actively listen to what patients are saying- about the challenges they face, what they need, and what really matters to them- we can design better systems, improve access to treatments, and make sure medicines are delivered and delivered in the ways that truly help people live better, healthier lives.

This shift has already led to stronger communication and collaboration between the pharmaceutical sector and Health Consumer Organisations (HCOs). It has also helped shared healthcare decisions that better reflect the real needs of the people they affect.



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Why this guide

This Guide has been developed to provide guidance for how health-care consumer organisations (HCOs) and pharmaceutical companies can work effectively together. It has been shaped by the principles and issues addressed in Medicines Australia Code of Conduct, recent policy advances in both the health and pharmaceutical industries, together with advice and feedback from representatives of both industry and HCOs. It is intended to enhance the nature and quality of partnerships and collaborations between HCOs and pharmaceutical companies and to build on the previous Working Together Guide (last updated 2015).

It is clear from all consulted that the timing is right to shift the balance from **predominantly transactional relationships** between HCOs and pharmaceutical companies based on the transfer of funds, to an increase in **transformational** (ie more collaborative demonstrated by mutual reciprocity) relationships to achieve better health outcomes for consumers.

It is time to reconceptualise the relationship in the context of a person-centred health system where the focus must be on the benefits to consumers and enhancing their health outcomes.

It is hoped that this document encourages HCOs and pharmaceutical companies to be **bolder, braver** and more **courageous** in their collaborative endeavours to make a difference to consumer health outcomes.



Who is it for?

This document is primarily for evidence-based pharmaceutical companies and HCOs that are incorporated. Smaller, voluntary HCOs, consumers, carers and families and the broader pharmaceutical sector may find the material relevant and it can be adapted to meet their needs.

It will help those who have never worked together before as well as those who have well established partnerships with multiple partners.

HCOs

HCOs represent the interests and views of health consumers, their families and carers. HCOs range in size and scope from small volunteer groups to large organisations. They also vary in their purpose. Some are condition related (ie heart disease, rare cancers) while others are more policy and advocacy oriented on broader policy and consumer health issues (ie CHF, state-based consumer health organisations). They generally promote views that are independent of government, the pharmaceutical industry and health care professionals and are not for profit.

Most HCOs receive little or no government funding and generate their income through fund-raising, grants and sponsorship activities.

Pharmaceutical companies

Research-based pharmaceutical companies are a type of pharmaceutical company. Other types include generic pharmaceutical companies, consumer medicines companies, complementary medicines companies and medical device companies. Pharmaceutical companies are committed to improving and maintaining the health of all Australians. They can vary in size and scope. Some of the larger pharmaceutical companies employ thousands of people in a range of departments including research and development, sales, marketing, corporate affairs, manufacturing, legal, compliance, IT, recruitment

accounting, market access and consumer advocacy. Companies with limited staff and departments may only manufacture and bring to market a select range of medicines. Many pharmaceutical companies are large multi-nationals with Australia being only one of the countries they service.

The pharmaceutical industry is regulated by the Australian Therapeutic Goods Administration (TGA). In addition, the research-based pharmaceutical industry peak body, Medicines Australia (MA) has an established Code of Conduct, to which all MA members must adhere. It is also common for individual pharmaceutical companies to have their own internal compliance processes. The compliance process can take additional time to complete, however, it is necessary to safeguard the integrity of sponsorships both for the protection of the HCO and the pharmaceutical company.

Both HCOs and pharmaceutical companies vary in size, structure and focus. This means they all work a little differently and growing a valued relationship can begin by asking questions about these areas.

How to use this guide

This Guide has 3 main sections:

Section 1: Why working together is important

Section 2: What we do together

Section 3: How we work together.

The Guide will be supplemented by a set of fact sheets that relate to various aspects of Working Together. These factsheets are referenced in the document where they are most relevant.

Factsheet 1: Australian and Global Health Context for Collaboration between Pharmaceutical Industry and HCOs

This factsheet provides an overview of the policy context, both within Australia and globally, that is relevant to pharmaceutical companies and patient organisations when they work together. There are also some key resources that have helped inform this document.

Factsheet 2: Summary of the Medicines Australia Code of Conduct

This factsheet provides a summary of the key principles underpinning the MA Code of Conduct for pharmaceutical companies.

Factsheet 3: Remuneration Framework of Health Consumers

This factsheet provides an overview of the policy context, both within Australia and globally, that is relevant to pharmaceutical companies and patient organisations when they work together. There are also some key resources that have helped inform this document.

Factsheet 5: Interacting with patient communities: Areas for pharmaceutical companies to consider

This factsheet provides an overview of the interactions HCOs seek, and advice on the information they look for from pharmaceutical companies to support these interactions. This factsheet was developed following research undertaken by the Patient Voice Initiative and Community and Patient Preference Research (CaPPRe).

Factsheet 4: Principles in Action across the different stages of partnership

This factsheet provides an overview of the policy context, both within Australia and globally, that is relevant to pharmaceutical companies and patient organisations when they work together. There are also some key resources that have helped inform this document.

Why working together is important

This section articulates the rationale, benefits and risks of working together.

Why Work together?

When the pharmaceutical industry works with HCO's they can shape the way medicines and treatments are developed to better address consumer needs, preferences and experiences. This can include aspects such as:

- how accessible medicines are to consumers,
- the cost to consumers,
- and the outcomes and benefits to consumer wellbeing and quality of life.

Consumer insights, input and perspectives are essential to pharmaceutical companies developing better treatment and medicines. Listening to consumer experiences, consumer challenges and exchanging insights can shape the future of medical research and disease management to more effectively address the needs of consumers.

Consumers with lived experience of a condition or disease can share unique insights into what it is like to live with a specific condition, how care is delivered, how that impacts on them, their carers and families. They can also provide helpful insights and feedback on how medicines and other treatments can affect their quality of life and meet their needs.

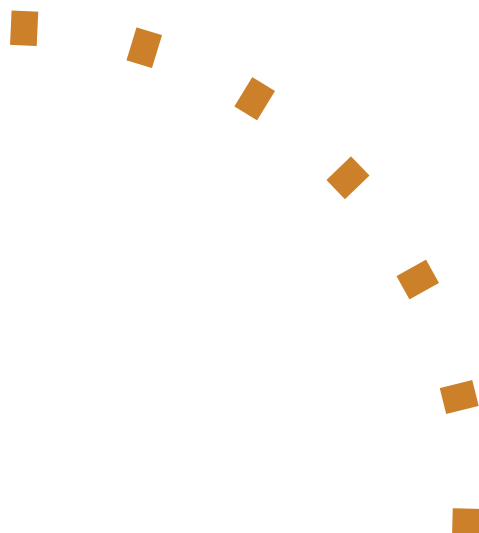
The consumer perspective is valued through encouraging open and transparent communication between consumers and industry. This involves including consumers in all aspects of the medicines lifecycle. This has the potential to lead to a more collaborative approach in how medicines are researched, developed and delivered to consumers which ultimately leads to better health outcomes.



To transform patients' lives, we must transform how we work together. Shared learning and problem solving offer a pathway to innovative healthcare and better outcomes for patients and their loved ones.



- Ann Single, CEO, Patient Voice Initiative



Benefits and Risks of Working Together

Benefits

The benefits to HCOs working together with pharmaceutical companies is that they can provide insights and perspectives on:

- access to medicines and treatment
- access and experience of clinical trials
- affordability and the value of the treatment
- side-effects

HCOs can also benefit from up to date information that can be incorporated during consultation and design phases leading to a more positive consumer experience.

Risks

Many HCOs have been hesitant to work with pharmaceutical companies because of perceived risks. The potential risks are:

- A large commercial company can potentially have significant influence
- There is a power differential between profit-making corporations and small, not-for-profit organisations
- Not maintaining independence whilst receiving funds from a pharmaceutical company.

Similarly, there are risks to the pharmaceutical industry due to the risk of being perceived to be too influential, however, the risks of working together can be mitigated if the principles outlined in the next section underpin the collaboration.

This includes maintaining independence, developing mutual trust and respect, and ensuring any funding and associated activity is transparent to all. Risks can also be mitigated if not-for profits undertake their due diligence and evaluate the pharmaceutical companies they receive funds from. The establishment of Medicines Australia as the peak body for research-based pharmaceutical companies, together with their established Code of Conduct, ensures detailed information is available that will help HCOs better understand the pharmaceutical companies they may wish to work with.

What we do together

This section provides an overview of the different types of activities that can be undertaken collaboratively and the different ways HCOs and pharmaceutical companies can collaborate on.

HCOs and pharmaceutical companies often welcome interactions if both feel valued and respected, and the rules of engagement (ie funding or payments) are clearly communicated. In addition to specific projects, some HCOs may value attending events such as briefings and introductions to key people in an informal capacity as well as being alerted to resources and events.

Types of activities

Collaborations can take a variety of forms and various activities can be undertaken, including:

- Campaigning and advocacy
- Events and meetings
- Funding in the form of grants for a project, sponsorship for events, professional development
- Co-design with consumers of information and support for consumers
- Accessing consumer insights and opinions and involvement in advisory structures
- Capacity building, including supporting HCOs to be able to achieve better outcomes for their members
- Co-design of educational activities, tools and resources suitable for consumers and their carers
- Research and development
- Training

Example activities:

One-off projects that are time-limited

A one-off project is for a fixed period. Examples include donations, sponsorships or educational grants to undertake specific activities. In some cases, this support can involve no further return to the company beyond an agreed acknowledgement process –(eg a reference in the HCOs annual report).

Short-term projects

Short-term projects may span one to three years as they are more substantial activities such as research, training or capacity building. These usually require HCOs and pharmaceutical companies to establish a more formal partnership. This enables more transparency about funding, deliverables, and the roles and responsibilities of each partner.

Example: Sanofi has provided a grant to National Aboriginal Community Controlled Health Organisation (NACCHO) to provide scholarships to pharmacy students. In 2022, six scholarships were offered which provide subsidy and support for Aboriginal and Torres Strait Islander pharmacy students and aimed to build the Aboriginal and Torres Strait Islander pharmacist workforce. The Scholarship program, which began in 2022 has been extended until 2025, demonstrating Sanofi's commitment to Aboriginal and Torres Strait Islander communities.

Pharmacist Scholarships 

Longer-term relationships

A longer-term relationship usually takes the form of a collaboration in which a pharmaceutical company and HCO work together on areas of common interest. Each partner makes contributions to the relationship, such as funding, the sharing of information, education, training and support. The partners benefit from working together bringing different strengths to achieve goals that might be beyond their reach if they worked on their own.

Example: Eczema Support Australia's ongoing relationship with Sanofi "What can we do to support the wonderful work you are doing for your eczema community." This question from Sanofi's Public Affairs Manager sparked the commencement of educational projects, capacity building and advocacy between Eczema Support Australia and Sanofi, their first industry partner. In turn, it gave Eczema Support Australia the confidence to build relationships with other industry partners. Open communication and mutual respect contributed to the growth and effectiveness of Eczema Support Australia.

“

We recognise the critical support that HCOs provide to people all across Australia. We're proud to support a variety of initiatives across the community that deliver better health outcomes for Australians every day.

”

- Liz Selby, Country Lead and Head of
Pharma Sanofi ANZ



How we work together

This section outlines the principles that need to underpin effective collaborations. Each principle includes a statement of purpose, issues to consider, practice guidelines and examples.

Principles

Fundamental to productive and valuable collaborations between HCOs and pharmaceutical companies is a strong relationship based on core principles. The six key principles are:

1. Valuing the consumer perspective
2. Clarity of purpose
3. Independence
4. Transparency and accountability
5. Integrity
6. Confidentiality

These principles are not mutually exclusive but each make a unique contribution.

These six principles align well with the overarching principles from the **Consensus Frameworks for Ethical Collaboration**. 

The primary purpose of the Consensus Frameworks for Ethical Collaboration is to “**guide ethical collaboration between Consumer organisations, healthcare professionals and the pharmaceutical industry in support of high quality Consumer care**”






And their overarching principles are:

- Put Consumers First
- Support Ethical Research and Innovation
- Ensure Independence and Ethical conduct
- Promote Transparency and Accountability.

Given pharmaceutical companies and HCOs come from different perspectives and have different approaches to health challenges, the exchange of ideas, within an ethical framework and without compromising independence, ensures consumers have a voice in the development of the treatments and underpins effective collaboration.






Valuing the Consumer Perspective

Principle	<p>Medicines are core to an integrated approach to treatment of illness. Gaining consumer insights and involving them in all aspects of the medicines lifecycle including research and development, clinical trial design, access, use and affordability are key to providing better health outcomes.</p> <p>Ensuring that relationships are focused on benefits to consumers is essential to a consumer-centred health system.</p>
Intent	<ul style="list-style-type: none"> • Consumers need to be at the centre of the partnership. Primary focus is on how the partnership will improve consumer health outcomes. • Listening to consumer needs, preferences and experiences can shape the future of medical research and disease management and lead to better health outcomes. • Providing balanced evidence- based information on medicines and treatment, accessibility and effectiveness has the potential to increase consumer health literacy about health conditions.
Issues to Consider	<p>For Industry</p> <ul style="list-style-type: none"> • How do you propose to learn from consumers or incorporate consumer knowledge? • Have you developed consumer engagement frameworks and policies? Are they publicly available? • How and when are consumers and HCOs remunerated? • Is the research evidence-based and relevant to consumers? <p>For HCOs</p> <ul style="list-style-type: none"> • Is the company aligned with the values of your organisation? • What are the company's engagement policies and practices? • How do they intend to use consumer insights? • What are their remuneration policies? • How early in the medicines lifecycle process will they consult with consumers and HCOs? • How does the company protect consumer data including medical information?
Principle in Action	<p>For Industry</p> <ul style="list-style-type: none"> • Services provided by consumers should be remunerated appropriately and be commensurate with the services being provided and applied consistently. • A public document about your consumer engagement framework including your company's rules of engagement, (eg how you apply the Code of Conduct, how contact can be initiated, how and when any reimbursement is offered) needs to be provided. <p>For HCOs</p> <ul style="list-style-type: none"> • Consumer outcomes must be the key focus of any partnership between companies and HCOs. • Projects should put the consumer first, ensuring it is built around consumer needs from the start and involving them or reflecting their views at every stage of the journey. Involvement of consumers early in the process is desirable. • Support the principle of all “human research must have legitimate scientific purposes that aim to improve health outcomes and be ethically conducted (Consensus Framework, page 3)
Example	<p>Bristol Myers Squibb: Facilitating early and continuous engagement of patient communities in Health Technology Assessment (HTA) Processes. This discussion paper  explores themes important to early and continuous engagement of the patient community in HTA processes in Australia.</p>
Related Resources	<p>MA Code Section 11 </p> <p>Consensus Framework </p> <p>Global Remuneration Project </p> <p>Patient Voice Initiative </p> <p>Factsheets 1,2,3 & 5</p>



Clarity of Purpose

Principle	Collaborations can take many forms. It is important to be clear about the purpose of the collaboration including both benefits and risks.
Intent	It is important that collaborations are based on mutual understanding and respect. Each party needs to consider the benefits and risks of the collaboration. Focusing on the ultimate benefit for consumers can help determine the purpose of the collaboration and assess whether there is a sufficiently shared sense of purpose between both parties.
Issues to Consider	<p>For both parties:</p> <ul style="list-style-type: none"> • Is the collaboration consistent with your organisations' policies and strategic intent? • Can you demonstrate the link between both parties' respective mission, purpose and strategic directions? • Is there alignment with each parties' values? • Are there any conflicts of interest or other issues that might make collaboration difficult or impossible? • What circumstances would cause you to need to end the collaboration?
Principle in Action	<ul style="list-style-type: none"> • A clear shared purpose and the scope of the collaboration are both documented in a written agreement • Clear statement of purpose of the collaboration communicated to members and stakeholders providing a rationale and any associated funding • Disclosure of the collaboration is visible on both parties' websites and in relevant reports and declared as an interest in relevant meetings and presentations.
Example	Biogen's MS Motion campaign  with collaboration from people with multiple sclerosis, and in consultation with MS Australia, with an agreed purpose to increase awareness and education amongst the general population and healthcare practitioners about the need for speedy, early diagnosis and management.
Related Resources, Projects	MA Code Section 12  Factsheets 1,2&4

Independence

Principle	It is vital for the integrity and credibility of HCOs that they protect and maintain their independence from all funders, partners and collaborations. Pharmaceutical companies need to also protect their reputation when entering a collaboration. The independence of the HCO in a collaboration is important for both parties.
Intent	<p>This principle is designed to safeguard the reputations of both parties. HCOs have a legal responsibility to act in accordance with their constitutions and objectives and need to ensure that these are not improperly influenced by funders and collaborators whether these are pharmaceutical companies or other entities.</p> <p>When a HCO collaborates with a pharmaceutical organisation, its independence can come under public and media scrutiny. This means that each party needs to be prepared to be proactive and transparent in explaining the nature of the collaboration to stakeholders and the public, if required.</p>
Issues to Consider	<p>For HCOs:</p> <ul style="list-style-type: none"> • Do you have more than one funder or partner for a particular activity as this reduces exclusivity and potential influence by a single funder? • Will you have editorial independence over materials, meetings and conference agendas and do you have clarity over intellectual property issues arising from the collaboration? <p>Both parties:</p> <ul style="list-style-type: none"> • Do you understand the perspectives of the other including expectations and are you able to identify issues that may cause tension and need to be resolved? • Do you feel able to express views even when the other party doesn't agree? • Have you established guidelines for the use of logos and descriptions of medicines? • Do you need to seek independent legal advice before signing an agreement?
Principle in Action	<ul style="list-style-type: none"> • Nothing should be offered or provided by a company in a manner or on conditions that would have or be seen to have an inappropriate influence on a HCO • Diversity of funding sources for HCOs is encouraged to support independence • Any event (ie professional development or program) sponsored by a company must be seen to be advancing knowledge and all materials and content must be balanced, accurate, current and scientifically valid.
Example	<p>The Eye Connect service, co-designed by Macular Disease Foundation Australia (MDFA) with people living with age-related macular degeneration (AMD), was developed and implemented to address unmet support needs between clinical visits. While Novartis and other industry members contributed funding, MDFA retained full editorial and operational control, ensuring the service remained patient led. This collaboration exemplifies how funding can support innovation while safeguarding independence and integrity. More than 600 patients have already benefited from the service. Find out more about Eye Connect .</p> <p>"Every time I have a breakdown over my eyes, I see your packs and I instantly feel better. It's nice to know there are people who genuinely care about you." - Eye Connect Participant.</p>
Related resources	<p>MA Code </p> <p>Consensus Framework </p> <p>Factsheet I&2</p>



Transparency and Accountability

Principle	Transparency, including the disclosure of relationships is essential for ensuring accountability, building trust and maintaining credibility and public confidence. It also allows for independent external scrutiny.
Intent	<p>A collaboration is most successful when consumers and the community trust that the aim of the relationship is to deliver the best possible health outcomes. The collaboration should be open and publicly transparent. It should be declared, in forms appropriate to different audiences, while still retaining the privacy entitlements of the parties involved.</p> <p>It is therefore important that when a HCO and pharmaceutical company collaborate, they consider how to avoid any perception that one party has unfairly or inappropriately influenced or compromised the other. Transparency should be regarded as “business as usual” in relation to all collaborations.</p> <p>Both parties should demonstrate that the resources that have been aligned to specific activities have been used appropriately and that agreed outcomes have been achieved.</p>
Issues to Consider	<p>For HCOs:</p> <ul style="list-style-type: none"> As well as direct financial transactions, what in-kind (value transfer) contributions are being made that are often through third party organisations such as research and public affairs agencies? You may want to consider disclosing these as well. <p>Both parties:</p> <ul style="list-style-type: none"> How will you report the value, source and intent of the funding? How will you report outcomes and achievements or progress to date? How will you demonstrate accountability to member and/or shareholders for all collaborations? What information will you disclose as well as how? The easier the information is to find, the less likely that someone will complain the organisation has something to hide Do you have plans to take part in other work for which this collaboration may be a barrier?
Principle in Action	<ul style="list-style-type: none"> Business arrangements between partners should not inappropriately influence their practice, compromise their integrity or independence or relationships with consumers. They should be transparent. A HCO and a pharmaceutical company may consider appropriate methods for reporting the results of their relationship to the key stakeholders and the wider Australian community. Accountability requires effort, so some time should be spent carefully considering the actions each partner will take to remain accountable. HCOs should develop and publish an explicit process for how they manage conflicts of interest, including any potential conflicts of interest arising from sponsorship.
Example	Any pharmaceutical companies that are Medicines Australia members are required to provide information regarding any formal relationships with HCOs for publication on the website  under a provision of the Code of Conduct. Participating HCOs should be aware that details of sponsorships will be publicly disclosed, including monetary values.
Related resources	MA Code Section 15.3  Factsheets 1,2,4 & 5

Integrity

Principle	Both parties to always be open and honest and act with integrity. Parties should not enter, or remain in, a collaboration which puts their integrity at risk.
Intent	<p>For a collaboration to be successful, from the outset both parties should be direct and honest about what they hope to achieve. They should be clear about their expected roles and responsibilities, and any constraints that might limit their ability to perform them. Both parties in the relationship should always feel free to raise issues and speak openly and should not feel pressured by the other partner.</p> <p>Fairness is essential during the negotiations to establish the relationship, throughout the relationship, and at the completion of the relationship. It is important to agree at the start on how each partner will be acknowledged throughout the collaboration. Acknowledgement can take many forms, such as written acknowledgements in educational resources, co-branded logos, websites and annual reports.</p>
Issues to Consider	<p>For HCOs:</p> <p>HCOs need to consider the following before entering a collaboration:</p> <ul style="list-style-type: none"> • the financial status, values, ethics of the pharmaceutical company • the company's track record in working with HCOs • the company's policies and positions on various matters (ie clinical trial data). <p>Both parties:</p> <p>If the goal of the collaboration is to create materials, such as educational resources, have you agreed on the ownership of the resources and who will hold intellectual property (IP)? For example, if a consumer booklet is developed the HCO and the pharmaceutical company should agree on the ownership of its ongoing use, future reprints and so on. In addition, appropriate arrangements to bring the relationship to a close should be part of any agreement to work together.</p>
Principle in Action	<ul style="list-style-type: none"> • Not proceeding with a collaboration that has potential to compromise integrity of either party • Other relationships that may be relevant to or impact the collaboration should be declared in accordance with anti-bribery and corruption legislation as well as Competition and Consumer law • Each partner in the relationship should always feel free to raise issues and speak openly, and should not feel pressured by the other partner.
Related resources	<p>MA Code </p> <p>Factsheets 1,2,4 and 5</p> <p>Managing Conflicts Guide </p>

Confidentiality

Principle	The partners in a collaboration must respect the confidentiality and privacy of the relationship in accordance with existing legislation and regulation.
Intent	A significant benefit of collaboration is that pharmaceutical companies and HCOs can share scientific data and other information that is not publicly available. Some of this material may be 'commercial in confidence'.
Issues to Consider	<p>Before entering a collaboration, both parties need to consider:</p> <ul style="list-style-type: none"> • What information can be shared? • The terms under which it can be shared? • How it will be shared? • How security and privacy will be protected? • What will happen if there is a breach?
Principle in Action	<ul style="list-style-type: none"> • Documented agreement on what information will be shared, how it will be shared and the terms and conditions • Ongoing accountability for when and where information was shared • Risk management plan for potential breaches.
Example	<p>PatientVoice Initiative Resource Library has documents addressing privacy and confidentiality in relation to consumer data.</p> <p>PVI resource library </p>
Related resources	<p>MA Code </p> <p>Factsheets 1,2,4&5</p>

How the guide was developed

This Guide has been developed by Medicines Australia in collaboration with Consumers Health Forum of Australia (CHF), the nation's peak body for health consumers. The aim of the project was to update the previous Working Together Guide, taking into consideration advances both in Australia and internationally.

This Guide also builds on similar work undertaken by colleagues in the global pharma community, the International Federation of Pharmaceutical Manufacturers and Associations (IFPMA), and The Association of the British Pharmaceutical Industry (ABPI) as well as the work of the Patient Engagement Management Suite's work on global remuneration. These are outlined in factsheets with links provided.

A Project Advisory Committee was established to provide advice and feedback. Members of the Project Advisory Committee included:

Petrina Keogh

Senior Manager, Stakeholder Relations
Medicines Australia (Co-Chair)

Leanne Wells

CEO, CHF (Co-Chair) until Aug 2022

Jo Root

Manager, Policy & Research, CHF from Sep 2022

Hayley Andersen

Head of Patient Advocacy & Policy, BMS

Jamie Nicholson

Corporate Affairs Manager, Roche

Melanie Funk

Founder, Managing Director, Eczema Support Australia

Sharon Millman

CEO, Lymphoma Australia

Richard Vines

CEO, Rare Cancers Australia

Ann Single

CEO, Patient Voice Initiative

Debra Letica

Consumer

Consultations were also undertaken with a wider range of pharmaceutical companies and HCOs. The format, content and structure of this document has been informed by these consultations and co-designed with the Project Advisory Committee.

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Being part of the Project Advisory Committee for this guide was an opportunity to contribute to a practical and accessible pathway for strong, transparent partnerships between health consumer organisations and pharmaceutical companies. Collaborating with Medicines Australia and CHF, we worked to ensure this guide reflects real-world experiences and practical insights, making it a valuable resource for building ethical and impactful relationships that truly benefit consumers.”

- Melanie Funk, Managing Director,
Eczema Support Australia



Glossary of terms

Consumer

A consumer is a person who uses (or may use) a health service, or someone who provides support for a person using a health service. Consumers can be patients, carers, family members or other support people. The term consumer in this document includes: “**Individual Patient**” is a person with lived experience of an illness or health condition and a recipient of health care services that are delivered by healthcare professionals. She/he may or may not have technical knowledge in R&D or regulatory processes, but their main role is to contribute with their lived experience. “**Consumer Advocate**” is a person who has insight and experience in representing a larger group of consumers living with a specific condition or has experience in advocating for more general health consumer issues. They may or may not be affiliated with an organisation. “**Consumer Expert**”, is a person who, in addition to their lived experience, has the technical knowledge in R&D and/or regulatory affairs through training or experience.

Consumers Health Forum of Australia (CHF)

CHF is Australia’s national peak body for health consumers.

Healthcare Consumer Organisations (HCOs)

Healthcare consumer organisations vary in size, some are incorporated and some are not. They provide a range of services to consumers, carers and their families including information, advocacy and education and training. For the purposes of this document, reference to HCO collectively includes patient organisations and patient representatives as well as state-based consumer health organisations.

Medicines Australia

Medicines Australia leads the research-based medicines industry of Australia. Its members discover, develop and manufacture prescription pharmaceutical products, biotherapeutic products and vaccines that bring health, social and economic benefits to Australia. Members invest in Australian medical research and take local discoveries and developments to the world.

Medicines Australia Code of Conduct

Medicines Australia’s Code of Conduct sets the standards for the ethical marketing and promotion of prescription pharmaceutical products in Australia. It complements the legislative requirements of the Therapeutic Goods Regulations and the Therapeutic Goods Act, which also apply to pharmaceutical companies.

Patient

A patient is a person with lived experience of an illness or health condition and a recipient of health care services that are delivered by healthcare professionals.

Patient Organisations

Patient organisations are non-government organisations often focused on a particular disease/ health condition or group of conditions. (eg Eczema Support Australia, Heart Foundation, Lymphoma Australia)

Patient Voice Initiative (PVI)

The Patient Voice Initiative is a collaboration between patients (or health consumers), researchers and industry working towards improving the patient voice in the Australian health system. It is an association incorporated in New South Wales, Australia.

Pharmaceutical Companies

Pharmaceutical companies are commercial businesses licensed to research, develop, market and/or distribute drugs most commonly in the context of healthcare. This brings with it enormous responsibility to ensure the safety and health of consumers, to behave ethically and to put the best interests of consumers at the centre of everything they do.

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Patients, and Patient Advocacy Groups, play an invaluable role in shaping the future of healthcare. They can shed light on the realities of living with specific conditions, the efficacy of treatments, and the impact on overall quality of life for themselves, their families and the broader community, which may not be captured in clinical trials. By actively listening to patient experiences, challenges, and preferences, we can create better systems, make access easier and improve disease management to address unmet needs and improve health outcomes together for patients and their families. ”

- Matt Zeller, Country President ANZ, Novartis



