

Factsheet 5: Interacting with Patient Communities: Areas for Pharmaceutical Companies to Consider

**Working
Together**

Our research* found patient organisations, patient advocates and online patient communities vary in the interactions they seek, but often value the following:

To feel valued & respected

The company offers a genuine relationship that meets shared goals & is not tokenistic or limited to a transactional relationship.

Rules of engagement

There is transparency around why, when and how patient communities can work with the company and how this can be initiated; information about how the company applies the Code of Conduct's principles and a clear point of contact.

Patient knowledge

The company shows a willingness & desire to learn about patient communities. They recognise that patient communities have expertise that they lack, such as insights or evidence about patients' needs, preference &/or experiences, & health policy perspectives, knowledge of healthcare practice and variation, patient sector knowledge, networks, etc.

Information on products or treatments

The company provides easy to understand, balanced information on their products relevant to the Australian setting, including its registered/unregistered products, & product status in Australia.

Involvement in product or treatment lifecycle

The company invites participation throughout the lifecycle; from identifying unmet needs and priorities, protocol, clinical trial designs, additional patient evidence, execution, reporting of research, implementing access to outcome, and withdrawal from market.

Early access

The company works with patient communities to bring more early access pathways to patients including clinical trial & access programs.

Education

The company facilitates access to toolkits; training; health system and policy briefings, events, meetings, conferences & introductions to key people.

Capacity building

The company supports the co-design of educational resources and training for patients.

Funding

The company provides general funding to help patient groups, online communities and patient advocates achieve their goals.

Payment

The company pays for contributing lived experience expertise to company events, meetings, projects and materials. It provides clear and transparent information about how payment works and how it will be offered.

Registries and databases

The company supports co-design, access, development and/or maintenance of patient-owned registries and databases relevant to patient community needs and to support Australian healthcare decision making.

Patient organisations, patient advocates and online patient communities vary in how they want to interact with pharmaceutical companies, and companies differ in how they interact with patient communities. Our research* suggested that clear and transparent published information (or guidance about how to easily access it) in the following areas is sought by patient communities to support interactions with companies.

Areas to Consider

- Point of contact for patient communities
- How Code of Conduct is applied; i.e. how and when you interact with patient communities, who you interact with, what can and can't happen
- Balanced information on products, including registered and unregistered products, and product status in Australian
- Common funding expectations, e.g. transparency, acknowledgement
- Information about education and capacity building opportunities
- Early access options (including trials and compassionate access)
- How reimbursement of lived experience works and when it will be offered
- Approach to lifecycle involvement of patients
- Goals for working with patient communities



Patient Voice Initiative

*You can use this QR code to find out more about our research to bench mark improvements in interaction:



Find out more

The Working Together Guide is a guide to relationships between health consumer organisations and pharmaceutical companies.



Working Together Guide



Factsheet #1: The Pharmaceutical Industry's Code of Conduct; What Companies Can and Can't Do



Factsheet #2: The Pharmaceutical Industry's Code of Conduct; What Companies Can and Can't Do



Factsheet #3: Remuneration Framework of Healthcare Consumers



Factsheet #4: Principles in Action Across the Different Partnership Stages



MA Code of Conduct