

Factsheet 3: Remuneration Framework of Healthcare Consumers

– Principles for remunerating healthcare consumers for interactions with pharmaceutical industry

**Working
Together**

Principles

1. Right to fair remuneration
2. Transparency
3. Non-discrimination
4. Respect
5. Non-promotional scope
6. Consistency
7. Time invested
8. Disclosure of Conflict of Interest
9. Raise concerns
10. Contractual agreement with payment terms and covered expenses

Patient Community

- Individual Patients
- Carers/Caregivers
- Patient Advocates
- Patient Organisation Representatives

Scope of the Principles

The Principles apply at local, national, and international level and to remuneration for services provided by the patient community to pharmaceutical companies.

If local laws and regulations do not permit payments for such interactions, then the Principles are out of scope.

The Principles were developed through the evaluation of existing, variable approaches to remuneration of the patient community. They aim to improve consistency, equality and ultimately fairness.

How to use the Principles?

Advocate for their adoption

Pledge to integrate them in your work

Share with your colleagues and networks

Verify that they are followed in future

Who should use the Principles?

Pharmaceutical Companies and Pharmaceutical Associations

All functions that play a part in patient engagement and remuneration, this might include:

- Patient Engagement & Advocacy
- Legal, Ethics and Compliance
- Research and Development
- Medical Affairs & many others

What are the Principles?

The Global Remuneration Principles outline objective criteria on which remuneration is paid to the Patient Community, including those living with a condition (Individual Patients), Carers/Caregivers, Patient Advocates, Patient Experts, and Patient Organisation Representatives for the work undertaken with Pharmaceutical Companies and Pharmaceutical Associations.

The Principles were co-created by PFMD, in collaboration with Individual Patients, Patient Organisation Representatives, Pharmaceutical companies, and in alignment with Pharmaceutical associations. They complement pre-existing collaborative work and are internationally applicable.

The project is led by PFMD and has been guided by a Steering committee with representatives from: EPF, EUPATI, Gilead, Global Skin, OSK, MPE, Novartis, Patient Access Partnership, Servier, WECAN, Global Heart Hub.



Why Principles?

1. Address a need for Global Principles focused on remuneration based on co-created and ethical standards.
2. Increase transparency and fairness in remuneration approaches.
3. Promote remuneration good practices to drive change.
4. Build trust and respect between stakeholders.

How to use the Principles?

Patient Community

Share the Principles with your colleagues locally and internationally.

Present the Principles during meetings with members of your organization and network, e.g. at your annual meeting or Board meetings.

Leverage the Principles with pharmaceutical industry partners with a call to action for them to be adopted.

Use the Principles to advocate for yourself and your patient community for future interactions.

Pharmaceutical Industry

Share the Principles with colleagues responsible for implementing current remuneration processes and market rates, such as legal, compliance and finance.


Review your internal processes and procedures to ensure they are aligned with the Principles.

Integrate the Principles in company procedures for remuneration of the patient community across all relevant functions who partner with patients-applicable to all countries and functions.

Talk to your data provider and ask what needs to change in existing processes to reflect the Principles.

Australian Context

It is recommended that consumer participation and contribution to the health industry in Australia is remunerated. Consumers that participate in a range of meetings or workshops or share their insights and experiences “lived experience” to inform health services or the health industry (including pharmaceutical companies) should be supported by the payment of a sitting fee and the coverage of travel expenses, where appropriate. Consumer advocates are providing “lived experience” expertise and often take leave from their paid or voluntary work position to contribute and therefore should be compensated for

doing this. Across the HCOs in Australia there are varying rates of remuneration but as a Guide, the Remuneration Tribunal’s rates for offices not specified is one that is widely applied. Remuneration Tribunal.  However, as this factsheet outlines, the rate of remuneration should be based on the level of expertise required, task and amount of time. This should be used as a guide only.

Framework based on the Global Principles of Patient Focused Medicine (PFMD) for remunerating the patient community for interactions with the pharmaceutical industry.


1. The National Health Council (2021) Principles for Compensating Patients for Patient Engagement Activities, EFPIA (2019) Working Together with Patients Principles, Myeloma Patients Europe, WECAN and PFMD (2018) Guiding Principles on Reasonable Agreements between Patients and Pharmaceutical Companies, IFPMA (2020) Note for Guidance on Patient and Patient Organization Interactions


2. See National Institute for Health Research (2021) Payment Guidance for Researchers and Professionals, Canadian Institutes of Health Research (2021) Considerations When Paying Patient Partners in Research.

Find out more

The Working Together Guide is a guide to relationships between health consumer organisations & 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 #4: Principles in Action Across the Different Partnership Stages](#)

 [Factsheet #5: Interacting with Patient Communities: Areas for Pharmaceutical Companies to Consider](#)

 [MA Code of Conduct](#)