

Global Principles for remunerating the patient community for interactions with the pharmaceutical industry



01	Right to remuneration	
02	Fair remuneration	
03	Non-discrimination	
04	Respect	
05	Non-promotional scope	
06	Consistency	
07	Time invested	
08	Payment terms	
09	Reimbursement of related expenses	
10	Transparency	
11	Disclosure of Conflict of Interest	
12	Contractual party	
13	Written agreement	
14	Raise concerns	

HOW to use the Principles?



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

Patient Community

- Individual Patients
- Carers/Caregivers
- Patient Experts
- Patient Advocates
- Patient Organization 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.

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.

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

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

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 Organization Representatives for the work undertaken with Pharmaceutical Companies and Pharmaceutical Associations.

The Principles were co-created by PFMD, in collaboration with Individual Patients, Patient Organization Representatives, Pharmaceutical companies, and in alignment with Pharmaceutical associations. They compliment pre-existing collaborative work¹ and are internationally applicable.

WHY Principles?

01

Address a need for Global Principles focused on remuneration based on co-created and ethical standards

02

Increase transparency and fairness in remuneration approaches

03

Promote remuneration good practices to drive change

04

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



Others

Review what aspects of the Principles can apply to other interactions (e.g. academia or regulatory interactions with the patient community)

Integrate aspects of the Principles that are relevant for patient community interactions while consulting other best-practices²



Need support, have questions?
Please reach out to
nicole@thesynergist.org



For more information please visit
pemsuite.org/fmv

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](#)