



## Roche's Position on Partnering with Patient Communities

### Background

At Roche, we believe that patients, their caregivers, their families, as well as the patient organisations that support them (known collectively as "the patient community") play an integral role in today's health ecosystem.

Over the last few decades, patient communities have advanced their knowledge of the healthcare ecosystem and have established themselves as a key stakeholder in this space. As such, patient communities can provide an important overarching perspective in different disease areas, health-related topics or health system issues. They also provide critical input to advance our understanding of a patient's full experience – how they live, their needs and goals, what concessions they make in their lives, how they experience healthcare delivery in their local communities, and much more.

Furthermore, patient communities safeguard the rights of individual patients, and provide governments, payers, industry (i.e., pharmaceutical and diagnostic companies) and healthcare providers with insights on how best to support them and their caregivers.

These insights help shape the work we – as Roche – undertake across the globe. Our partnership with patient communities is integral to our business, as well as our commitment to being a patient-focused company.

We strive to embed patient input throughout the lifecycle of our innovations in a systematic way, starting in the earliest phases of development with research prioritisation, feasibility assessments, clinical trial design (including the validation of endpoints, patient reported outcomes measures, scheduled assessments) and spanning to regulatory authority discussions, real world data/evidence generation plans, patient access strategies and beyond. Partnership with patient communities also contributes to Roche's commitment to support the [UN Sustainability Development Goals](#) (SDGs), in particular SDG 3 on 'Good Health & Wellbeing.'

### Stakeholders Expectations of Trust

While we firmly believe that partnering with patient communities yields value for patients, society and Roche, we recognise that the collaborative work we undertake is often subject to scrutiny. Stakeholders like public institutions (regulatory authorities, governments, payers), non-governmental organisations (NGOs), media and the general public closely monitor our industry's work with patient communities to ensure that we – as a collective – maintain transparency in our interactions and do not unduly influence their strategies, their plans, their decisions, information they may disseminate and their advocacy efforts related to access.

In order to maintain public trust in our interactions, we adhere to all laws and regulations, as well as follow all global and local published codes/guidelines on interactions with patients and patient organisations (*see list of some international guidelines below*). We have also built our engagement



approach to align with the governance frameworks established by each of our individual patient community partners.

## Key Principles, Philosophy and Commitment

Roche's work with patient communities is rooted in the following key principles: mutual value, integrity and equity, independence, mutual respect, and transparency.

*Mutual Value:* We strive to partner with patient communities in a way that reflects our commitment to improving the quality of life of patients, and focuses on building longer-term relationships based on a clear understanding of our shared priorities, needs, goals and interests. These partnerships enable us to develop better, more personalised medicines, diagnostics and integrated digital care solutions and customised support services to deliver outcomes that matter most to patients.

*Integrity and Equity:* Ethics and compliance play a key role in our mission of "doing now what patients need next." At Roche, we believe our commitment to responsible business behavior goes beyond legal compliance and includes the highest standards of integrity, fair remuneration, benchmarking against best practices and transparent reporting. Roche employees engaging with patient communities are expected to comply with all international, national and local laws, regulations, industry codes, as well as internal policies that govern our work with stakeholders.

*Independence and Mutual Respect:* In order to maintain strong partnerships with patient communities, Roche believes it is critical that each organisation maintain its independence through the course of the relationship. It is vital that patient communities not feel obligated or compromised as a result of their partnering with Roche, so we make every effort to maintain, respect and promote the independence of the communities with which we work. We also commit to listening to them, to striving to understand their needs, to acting on their advice, and to reporting back on where their feedback has or has not been incorporated.

*Transparency:* We strive for openness and transparency in all that we do. We believe that transparency is critical to a business environment that is both productive and responsible. For this reason, we disclose all funding or non-monetary support provided to patient organisations worldwide in a clear manner as part of our standard business reporting practices. This list is updated annually and can be found on our corporate website at [www.roche.com](http://www.roche.com) within the [Patient Organisations](#) section of the company's Sustainability overview. In addition, the Roche Corporate Executive Committee has endorsed the [Roche Directive on Collaborating with Patient Groups and Patients](#) that provides guidance for how our employees may partner with patient communities. This Directive applies to all Roche companies and all third parties (e.g., agencies) who work on behalf of Roche. This Directive is also benchmarked against industry best practices



on an ongoing basis and is amended, as needed, to ensure our practices are reflective of community expectations and needs.

Further to the principles highlighted above, Roche's approach to partnering with patient communities is built on the core philosophy that everything we do *for* patients, we do *with* patients – as equal partners every step of the way.

Our commitment to patient partnership and delivering the highest value for the community is a shared goal across our organisation. While we have a primary point of contact model in place to offer patient communities a simple and lean way to engage with our company, we work collaboratively and cohesively as 'One Roche' to deliver on our promise. This means that all Roche colleagues take on the shared responsibility for incorporating the patient voice into their work. Only through this collaborative approach can we hope to achieve our overarching company mission of *delivering more benefit to patients at a reduced burden to society*.

*This position paper was updated and approved by the Corporate Sustainability Committee on June 2, 2020 and was adopted, as well as entered into force by the Corporate Executive Committee in April 2021.*

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#### Published International Documents for Working with Patient Communities

- International Federation of Pharmaceutical Manufacturers and Associations (IFPMA): [Code of Practice 2019](#)
- European Federation of Pharmaceutical Industries and Associations (EFPIA): [Code of Practice](#)
- European Federation of Pharmaceutical Industries and Associations (EFPIA): [Working Together with Patient Groups](#)
- European Federation of Pharmaceutical Industries and Associations (EFPIA): [Principles for Remunerating Patients, Patient Organisation Representatives & Carers for Work Undertaken With the Pharmaceutical Industry](#)
- Pharmaceutical Research and Manufacturers of America (PhRMA): [Principles on Interactions with Patient Organizations](#)
- European Patients' Academy (EUPATI): [Guidance on Patient Involvement](#)
- Patient Focused Medicines Development: [The Book of Good Practices](#)
- Clinical Trials Transformation Initiative: [CTTI Recommendation on Effective Engagement with Patient Groups Around Clinical Trials](#)