

Roche Position on Collaborating with Patient Groups and Patients

Background

Roche collaborates with the patient community which includes patient groups, patient organisations, patient advocacy groups, expert patients, individual patients, caregivers and family members of patients (“patients”). In the past the pharma and diagnostics industry (“the industry”) made decisions in the development and product lifecycles of its medicines and diagnostics on behalf of patients. However, the healthcare environment has rapidly changed in the last years and patients are more and more involved in their healthcare decision making and choices. As a consequence of this change, patient centricity has become a very important topic for the industry. Today, as a matter of daily practice, the industry collaborates with patients in different areas ranging from clinical trial design and endpoints, drug development to market access. This change has created meaningful value for patients, the industry, the healthcare system and society as a whole.

Stakeholders’ Expectations and Concerns

A variety of stakeholders, including authorities, NGOs, media and the general public are carefully monitoring interactions between the industry and patients. There exist concerns that the industry abuses the interactions with patients to unlawfully promote their products. The stakeholders expect that principles and standards of integrity, independence, respect, equity and transparency are consistently applied in all these interactions.

Roche’s Purpose and Position

Roche understands the expectations and concerns as described above and is committed to put in place adequate safeguards and governance to protect the interests of patients. Roche sees an enormous value in partnering with patients, since Roche can build on their unique experience, expertise and perspectives. In particular, the collaboration with patients enables us to understand how best we can incorporate the patient perspective while developing our medicines and diagnostics.

Roche’s collaboration with patients is paramount to achieving Roche’s purpose being “Doing now what patients need next”. Roche is committed to collaborate with patients through a transparent dialogue to properly understand the urgent medical needs of patients. Roche’s commitment to patients is demonstrated in many ways throughout the Roche Group and is fundamental to what we believe to be Roche’s most significant contribution to society: to create, produce and market innovative solutions of high quality for unmet medical needs. Roche and the patient community share a common vision to improve patients’ access to innovative medicines and diagnostics.

Building a sustainable partnership with patients is an important way for Roche to honour its commitment and responsibility to patients and society as a whole. Accordingly, it contributes to Roche's commitment to support the UN Sustainability Development Goals (SDGs)¹, in particular SDG 3 on health, within the sphere of Roche's business strategy.

Roche applies high ethical standards in all collaborations with patients. Key principles are integrity, independence, respect, equity, transparency and mutual benefit. We enter into relationships committed to sustaining a long-term working partnership, which also reinforces the credibility and independence of the involved parties. For transparency reasons, Roche discloses on its website² the names of patient groups that have received funding or significant non-monetary support from Roche, as well as those patient groups that Roche has engaged to provide significant contracted services. This list is updated annually. In addition, to reflect the changes that occurred in the environment of interactions with patients, the Roche Corporate Executive Committee has revised the Roche Directive Collaborating with Patient Groups and Patients³ that specifies the terms and conditions for Roche employees' collaboration with patients. The Directive applies to all Roche companies and all third parties, e.g. agencies, which are working on behalf of Roche. Roche is committed to continuous improvement by benchmarking the Directive against best practice and, if appropriate, to amend it.

Current Collaborations and Initiatives

On our Roche sustainability website⁴ we inform in a transparent way about our engagement and dialogue by including stories evidencing our successful collaboration. In addition we can report on our collaboration with patients on a global scale at the Roche owned annual event named *International Experience Exchange for Patient Organisations (IEEPO)*⁵ where patients share their insights and perspectives. Roche is actively collaborating with patient groups, by way of example with *Friends of Cancer Research*⁶ in the area of real world data to find relevant solutions for faster access to Roche's innovative medicines and diagnostics; and *the European Haemophilia Consortium*⁷ in the area of rare diseases with the objective to increase access to Roche's novel haemophilia treatment. Roche also recently launched the *ForPatients Platform*⁸, a global website that addresses the need for clinical trial layperson summaries, Roche clinical trial information and disease awareness.

¹ Pertains to SDGs 3 and 16

² Refer to <https://www.roche.com/sustainability/patientorganisations/patient-groups-list.htm>

³ Refer to https://www.roche.com/sustainability/approach/positions_policies_downloads.htm

⁴ Refer to <https://www.roche.com/sustainability/patientorganisations.htm>

⁵ Refer to Roche CEO Severin Schwan on the value of patient organisations at <https://www.roche.com/sustainability/patientorganisations.htm>

⁶ Refer to <https://www.focr.org/>

⁷ Refer to <https://www.ehc.eu/>

⁸ Refer to https://www.roche.com/research_and_development/who_we_are/how_we_work/clinical_trials/patient-platform.htm



Industry associations, e.g. EFPIA and MedTech Europe, have also initiated steps to address the legitimate demand from patient groups and patients to collaborate and dialogue with the industry. Roche is fully committed to contribute in shaping a regulatory environment which enables value based collaboration with patients.

This Position Paper was updated and approved by the Corporate Sustainability Committee on November 8, 2018 and was adopted by the Corporate Executive Committee on December 12, 2018 and entered into force the same day. It was reviewed in March 2019.