



# Our position on Engagement with Patient Organisations



## What is the issue?

Patients are at the heart of everything we do at GSK. Engaging with patient organisations helps us to better understand the experiences of patients and the disease they are living with. This in turn helps to guide our R&D, as well as our policies. At the same time, we hope that our support can help patient organisations to champion and represent the voice of the patient in the healthcare policy environment.

Rightly, there is significant scrutiny of the relationship between pharmaceutical companies and patient organisations. We have established rigorous standards to govern our interactions with patient organisations. These are aligned with our values and help to safeguard the independence of groups with whom we work.

This paper sets out our approach to working with patient organisations; why we engage with them; and the standards we apply to ensure our interactions are appropriate, ethical, and transparent.

## What is GSK's view?

- Patient organisations are crucial stakeholders within the healthcare debate, and we believe it is essential that the patient perspective is well represented before policy makers. We work with patient organisations from many therapeutic areas, not just those aligned with our core disease expertise. This helps us to better understand their needs and helps patient organisations to build their advocacy capabilities.
- We believe unequivocally in the independence of patient organisations – it ensures that they can represent their members' best interests. We are committed to ensuring that our collaborations with these groups are proportionate and appropriate. We do not promote our medicines to patient organisations (unless permissible under local laws and regulations); we do not ask patient organisations to promote our medicines on our behalf; nor would we ever ask them to endorse our medicines in any way. All discussions around disease management or medications are approved and carried out by our medical and R&D colleagues; we have robust governance in place to ensure interactions are independent from commercial influence.
- We have strict funding procedures that go beyond what may be legally required. With only two exceptions (see below for details), we will not provide any more than 25% of the total funding received by a patient organisation during any calendar year. This supports the long-term sustainability of patient organisations, as it minimises the chance of them becoming too reliant on GSK for support. It also reduces the potential for conflicts of interest.
- Transparency is fundamental to having open and constructive interactions with patient organisations. GSK was the first company to disclose all of our payments to patient organisations on our external website – a practice which has now become standard across the pharmaceutical industry.
- We have several platforms to ensure patients' interests are respected and we have embedded this into the way we work at every level of the company. These include a Health Advisory Board focused on Europe, set up in 2004. Through these forums, we consult and share our thinking with leading patient organisations on key GSK policies and external developments.

## Background

### Definition of a patient organisation

There is no globally recognised definition of a patient organisation. The term can cover a wide range of patient advocacy groups and patient support groups. Some provide education and information to their members, while others also advocate and influence healthcare policy. As an integral part of improving standards of care, patient organisations are important stakeholders for GSK, and we value the role they play in the healthcare environment. Examples of where patient organisations have recently helped shape our thinking are on medicines supply issues and how best to support patients in relation to decentralised clinical trials.

To help ensure the appropriateness of our interactions with patient organisations, we ask that in order to receive funding or take part in any joint work, the organisation must:

- Have the interests of patients at the core of their mission
- Be a credible, independent, and legitimate patient organisation with official or legal status
- Have patients and/or carers/caregivers on the board
- Have robust governance processes such as a constitution, bylaws, or an audit function
- Be transparent about funding, with an annual report or equivalent official documentation
- Be non-profit making

### Management and oversight

At a country level, we have a patient affairs lead, who coordinates work with their national patient organisations and works to ensure that our R&D and business strategies are informed by an understanding of patients' needs and concerns.

These roles sit within Medical or Communications and Government Affairs, operating separately from our commercial function. This reflects the robust governance we have in place to ensure engagement with patient organisations is independent from commercial influence.

To help standardise the work of the patient affairs leads, and to drive our patient-centred approach throughout the business, we have in place a Global Standard for Interacting with Patient Organisations. This covers the following areas:

- Type of funding available to patient organisations
- Documentation and disclosure procedures relating to the funding of patient organisations
- Various internal roles used to co-ordinate and oversee GSK's engagement with patient organisations including patient affairs leads and relationship managers

### Funding types and principles

GSK supports patient organisations across the world in several ways:



Core funding (i.e. an unrestricted grant to support the day-to-day running of a group)

- One-off project funding to help patient organisations conduct a specific event or activity
- In-kind support, such as agency support for media outreach

We believe that all patient organisations should function independently and consequently our funding adheres to the following principles:

- We will not provide more than 25% of the total funding received by a patient organisation during any given calendar year. The exceptions are for rare disease patient organisations (rare disease with low prevalence) or start-up patient organisations, which can receive up to 50% of the total funding, if approved by a senior manager.
- We do not ask to be, and will not be, the sole funder for major projects with patient organisations.
- We do not seek endorsement of our medicines from patient organisations.
- We do not fund individuals, in their capacity as representatives of patient organisations, to attend medical and other healthcare professional meetings (unless they are attending as a speaker or there is a specific patient work stream).

Each country, business unit or region has a Grants and Donations Committee in place for approving patient organisation funding, as well as a defined process for reviewing funding requests.

### **Disclosure of funding**

We disclose all support given to patient organisations on our external website, including financial support and/or significant indirect/non-financial support. We were the first company to disclose this information and in doing so have helped to provide a benchmark for the rest of the industry since 2007.