

Appendix A: Glossary of terms

Concept	Definition
Patient engagement	“The active, meaningful, and collaborative interaction between patients and researchers across all stages of health product R&D ... where decision-making is guided by patients’ contributions as partners, recognising their specific experiences, values, and expertise.” ¹⁴
Patient-centric	Aligned with the needs and experiences of patients and their families to achieve the best experience and outcomes for patients. ⁴¹
Community advisory boards (CABs)	A group of people living with a specific condition, a close family member or carer, and/or a member of a patient organization that works with the disease, who offer their expertise to representatives from biopharmaceutical industry and who advise several organizations in their disease area. CABs are autonomous, not related to or chosen by the developers. Through the network of European and national patient organizations, patients are informed, nominated, and selected by the patient community based on a job description. For more information, see the guidance document “Working with Community Advisory Boards: guidance and tools for patient communities and pharmaceutical companies.” ²⁰
Sponsor	A person, company, institution, group, or organization that oversees and/or pays for a clinical trial and collects and analyzes the data. Sponsors are represented by industry representatives.
EuroCAB program	The program, administered by EURORDIS, assists patient organizations in setting up and structuring a CAB for their disease area and includes some common principles and tools for patient groups and sponsors: capacity-building of patient advocates, peer-to-peer exchange of experiences across CABs, quality monitoring of the process and outputs of CABs, transparency and prevention of competing interests, promotion of the program, and evaluation of possible eventual scientific publications. ¹⁹
Health product	Any product that aims to alleviate the burden of a specific disease (eg, medicines and “solutions beyond the pill” such as technologies, services, or information materials).
Research and development (R&D)	The full life cycle of development of a health product, from discovery to commercialization and postmarketing activities.
Monitoring	The formative evaluation of patient engagement practices in order to strengthen them. ¹⁴
Evaluation	The systemic acquisition and assessment of information to provide useful feedback about the effects (direct and indirect outcomes) of patient engagement practices. ¹⁴
Framework	A defined structure that helps clarify the implicit theory of how a patient engagement initiative works.
Theory of change	A comprehensive visual narrative model of how and why a desired change is expected to happen in a particular context, developed by collaboratively mapping out all the “steps on the pathway to impact.” including what an initiative needs and does and how and why these lead to desired objectives being achieved. ⁴²
Metric	A qualitative or quantitative measure that provides a means of expressing achievement of a goal or ascertaining the consequences of a specific change. Quantitative metrics are reported as numbers, such as rates of change and ratios. Qualitative metrics are reported as words, in statements, paragraphs and reports. ¹⁴ The terms metric and indicator are sometimes used interchangeably.
Set of metrics	An agreed-upon group of metrics that relate to each other and align with a given context, with methods/tools to collect the information. ²²
Reflexivity	The capacity to reflect on (social) practices, assumptions, beliefs, and values and to challenge and change those that are undesirable through inquiry, dialogue, and learning. ²²