

## EUCOPE declaration of membership in other organisations and networks.

Name of organization / network	Description of membership
Advisory Board of the Data Analysis and Real World Interrogation Network (DARWIN EU)	EUCOPE is a member of the Advisory Board of the Data Analysis and Real World Interrogation Network (DARWIN EU). It provides strategic advice and recommendations to the DARWIN EU project team on the establishment of DARWIN EU capability and its use of the European Health Data Space.
Advisory Board of the European Rare Disease Research Coordination and Support Action consortium (ERICA)	EUCOPE is a member of the Advisory Board of the European Rare Disease Research Coordination and Support Action consortium (ERICA). It is a platform that aims to build on the strength of the individual 24 European Reference Networks (ERNs), integrating their research and innovation capacity.
Biotechnology Innovation Organization (BIO)	EUCOPE has a reciprocal membership with U.S.-based Biotechnology Innovation Organization (BIO). We exchange information on topics of relevance for our member companies, e.g. the ecosystem for small to mid-sized companies, IP, the European Health Data Space and data sharing.
EU Health Coalition	EUCOPE is a member of the EU Health Coalition. It is a multi-stakeholder initiative dedicated to: mapping the future of healthcare in Europe in order to make the most of the innovation at our fingertips, examining the role of the European Union in addressing the challenges we face and looking at how different sectors can diverge to deliver the best outcomes for patients in Europe.
European Alliance for Cardiovascular Health (EACH)	EUCOPE is a member of the European Alliance for Cardiovascular Health (EACH). It brings together leading European and international organisations with the aim to promote cardiovascular health as a policy priority at EU level. The Alliance strives for greater focus on improving cardiovascular health and reducing the burden of cardiovascular disease at European level.
European Alliance for Transformative Therapies (TRANSFORM)	EUCOPE is a member of the European Alliance for Transformative Therapies (TRANSFORM). It is a multi-stakeholder alliance that connects Members of the European Parliament (MEPs) and policy-makers with patient groups, medical experts and associations, scientists, researchers, industry actors, networks and other relevant stakeholders. TRANSFORM aims to foster effective dialogue and provide evidence-based policy recommendations to enable safe and timely patient access to cell and gene therapies, whilst ensuring the sustainability of healthcare systems.

European Expert Group on Orphan Drug Incentives (OD Expert Group)	EUCOPE is a member of the European Expert Group on Orphan Drug Incentives (OD Expert Group). It is a multi-disciplinary and cross-functional expert group that brings together representatives of the rare disease community, including researchers, academia, patient representatives, members of the investor community, rare disease companies and trade associations. EUCOPE is supporting the development of methodologies for Joint Clinical Assessments (JCAs) of Orphan Medicinal Products (OMPs) and recommendations for handling conflicts of interests in JCAs for OMPs in the OD Expert Group.
European Working Group for Value Assessment and Funding Processes in Rare Diseases (ORPH-VAL)	EUCOPE is a member of the European Working Group for Value Assessment and Funding Processes in Rare Diseases (ORPH-VAL). It is a working group of European rare disease experts that was formed in 2015, and comprises patient representatives, academics, politicians, regulators, payers and industry. ORPH-VAL provides recommendations to improve access to orphan medicines through development of common principles for pricing and reimbursement procedures for orphan medicines. The group, which was established in 2015 has published nine recommendations, to inform the assessment of OMPs, also as part of the future EU HTA procedure.
HERA Joint Industrial Cooperation Forum (JICF)	EUCOPE is a member of the Joint Industrial Cooperation Forum (JICF), the advisory body to the European Commission's Department for Health Emergency Preparedness and Response (HERA). The JICF discusses how to ensure that the EU is better prepared to react to future health emergencies. EUCOPE participated in regular calls with the EMA and the European Commission to monitor and report on potential drug shortages during the pandemic and continue to provide insights from our members in the JICF, in order to prepare the EU for future health emergencies.
Massachusetts Biotechnology Council (MassBio)	EUCOPE has a reciprocal membership with U.S.-based Massachusetts Biotechnology Council (MassBio). This serves to provide opportunities for building bridges between the innovative small and mid-sized companies of EUCOPE with the world's top biomedical ecosystem, and we share information on best-practices, and opportunities for engagement in Europe and Massachusetts.
Medical Device Coordination Group (MDCG)	EUCOPE is a member of the Medical Device Coordination Group (MDCG). It deals with key issues from the medical devices sector, from Notified Body oversight on standardisation to market surveillance, passing by international matters, new technologies and clinical investigation.
Rare Disease Moonshot	EUCOPE is a member of the Rare Disease Moonshot. It is a commitment and collaboration between seven organisations to break down the barriers to finding new treatments and cures for the world's rarest and severe conditions which currently have no therapeutic options, and which often affects the youngest patients.
RWE4Decisions	EUCOPE is a member of RWE4Decisions, a multi-stakeholder initiative commissioned by RIZIV-INAMI (Belgium). It is a learning network of payers, HTA bodies, regulatory agencies, clinicians, patient groups, industry and academic experts which aims to find agreement for what real world data can be collected for highly innovative therapies – when, by whom and how – in order to generate real-world evidence to inform regulatory, HTA and payers' decision-making.

Together for Rare Diseases (Together4RD)

EUCOPE is a member of Together for Rare Diseases (Together4RD). It is an agile multi-stakeholder initiative aimed at supporting European Reference Networks (ERNs) to collaborate with stakeholders to pursue opportunities that will address unmet medical needs of people living with rare diseases. Through our membership we work to unlock opportunities for collaboration in basic to translational research, clinical trials for rare and ultra-rare conditions, testing and accelerating innovative approaches to diagnosis and development and implementation of data/evidence generation initiatives.

