

Appendix 1. JARC Consensus panel

Blay Jean-Yves (Centre Léon Bérard), Brecht Ines (Pediatric Hematology and Oncology, Children's Hospital, Eberhard-Karls-Universitaet Tuebingen, Germany); Brechot Jeanne-Marie (National Cancer Institute, France); Cañete Nieto Adela (Spanish Registry of Childhood Tumours); Capocaccia Riccardo (Epidemiology and Prevention Editorial Board); Cavero Carbonell Clara (Foundation for the Promotion of Health and Biomedical Research of Valencia Region); De Angelis Roberta (Istituto Superiore di Sanità, Rome, Italy); De Lorenzo Francesco (European Cancer Patient Coalition); Dei Tos Angelo Paolo (University of Padua School of Medicine, Director of Pathology; Department of Oncology Azienda ULSS N. 2 Marca Trevigiana, Treviso, Italy); Della Porta Matteo (Leukemia Unit Cancer Center - IRCCS Humanitas Research Hospital & Humanitas University, Mialn, Italy; European Reference Network In Rare Hematological Diseases); Ferrari Andrea (Pediatric Oncology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Italy; European Cooperative Study Group for Pediatric Rare Tumors); Frezza Anna Maria (Medical Oncology Unit 2, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Italy); Gatta Gemma (Evaluative Epidemiology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Italy); Gronchi Alessandro (Department of Surgery, Sarcoma Service, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Italy); Janavicius Ramunas (Vilnius University Hospital Santaros Clinics Hereditary Cancer Competence Center Hematology, Oncology and Transfusion Medicine Center, Lithuania); Kearns P.R. (Institute of Cancer and Genomic Sciences, NIHR Birmingham Biomedical Research Centre, University of Birmingham, Birmingham, UK; European Society for Paediatric Oncology); Kozhaeva Olga (European Society for Paediatric Oncology); Licitra Lisa (Department of Oncology and Hemato-oncology, University of Milan, Italy & Department of Medical Oncology, Head and Neck Cancer Medical Oncology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori Milan, Italy); Marcos-Gracera Rafael (Epidemiology Unit and Girona Cancer registry, Oncology coordination plan, Oncology Catalan Institute); Manneh Isabelle (European Cancer Patient Coalition); Melegh Bela (Department of Medical Genetics University of Pécs, Hungary); Nicolai Nicola (Urology Unit, Testis surgery Unit Head, Fondazione IRCCS Istituto Nazionale dei Tumori Milan, Italy); Olry Annie (The Portal of rare Diseases and Orphan drugs-Orphanet); Rath Ana (The Portal of rare Diseases and Orphan drugs-Orphanet); Sandrucci Sandro (Sarcoma Unit, Department of Surgery, University of Turin, Turin, Italy, European Society of Surgical Oncology); Sekerija Mario (Croatian National Cancer Registry, Croatian Institute of Public Health) Van Eycken Liesbet (Belgian Cancer Registry); Vassal Gilles (Department of Clinical Research, Gustave Roussy, Paris-Sud University, Paris, France; European Society for Paediatric Oncology); Walsh Paul (Irish Cancer Registry); Weinman Ariane (EURORDIS).