

Registry of Patients with Primary Immunodeficiencies (PID) in Greece: A Systemic Approach

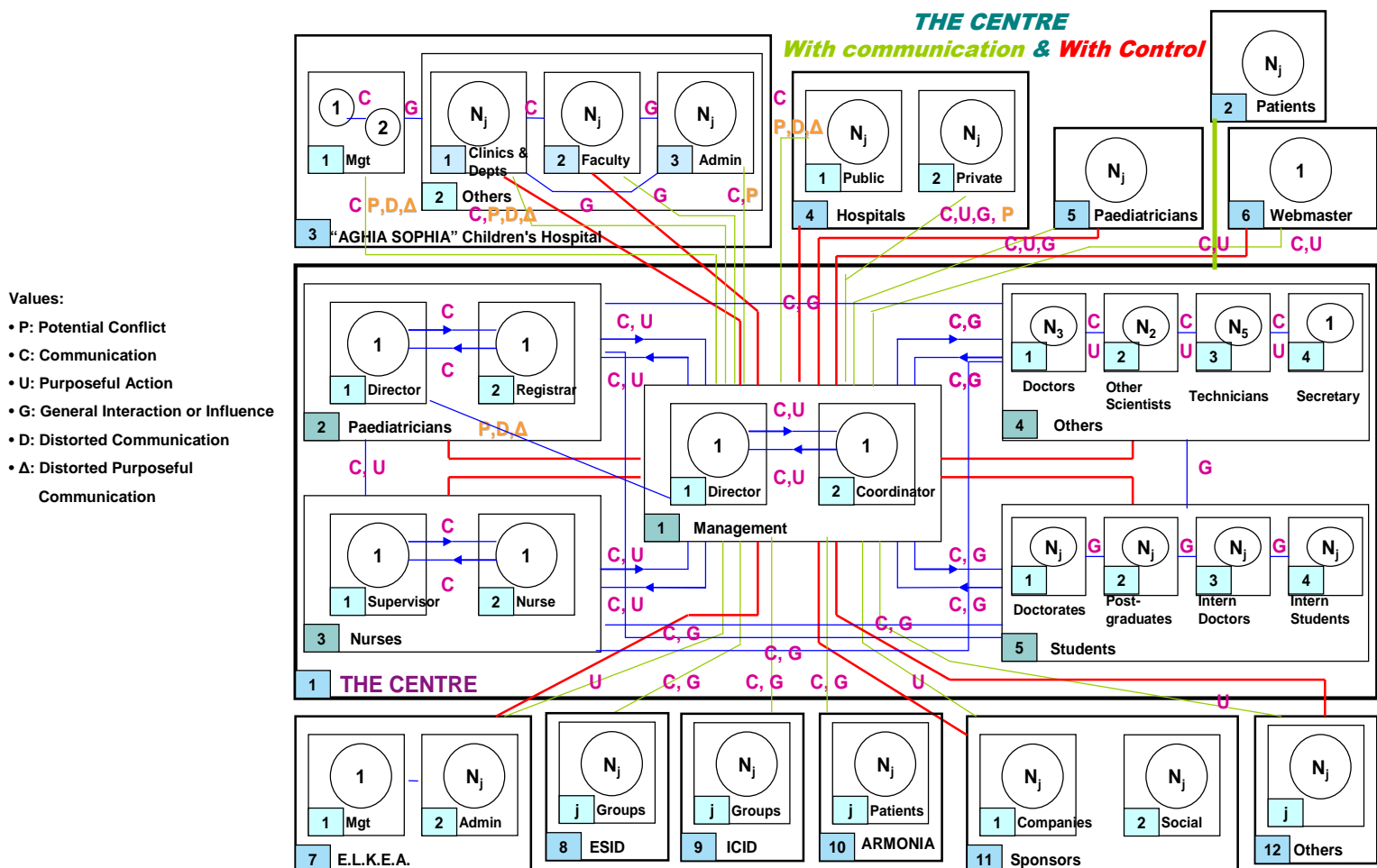
Penio Kassari ^{1,2,3}, Maria Kanariou ^{1,2}, Nikitas Assimakopoulos ^{3,4}

1. Dept. of Immunology-Histocompatibility, Specific Center & Referral Center for Primary Immunodeficiencies – Paediatric Immunology, "Aghia Sophia" Children's Hospital, Athens, Greece
2. "ARMONIA" – Hellenic Association of Friends of Patients with Primary Immunodeficiency – Paediatric Immunology, Athens, Greece
3. Certified Systemic Analyst Professional Program (CSAP), University of Piraeus - Research Centre / Hellenic Society for Systemic Studies (HSSS), Piraeus, Greece
4. Dept. of Informatics, University of Piraeus, Piraeus, Greece

Keywords: Primary Immunodeficiencies (PID), Registry Management, Professional Systemics, Design and Control Systemic Methodology (DCSYM)

Introduction: The need for the Registry of PID-patients derives from the rarity of these diseases, the lack of knowledge for their existence and their biomedical importance in relation to other diseases, the development of new therapeutic approaches and the great impact in the lives of the patients, their families and the community. The purpose of the study was to demonstrate the deployment of the Design and Control Systemic Methodology (DCSYM) for the Management of the Registry of Patients with Primary Immunodeficiencies in Greece. The study took place in Dept. of Immunology-Histocompatibility of the "Aghia Sophia" Children's Hospital, Athens, Greece, which is a Specific Center & Referral Center for Primary Immunodeficiencies – Paediatric Immunology. The research has the endorsement of the 1st Health Region of Attica Prefecture (1st YPE Attikis).

Methodology: DCSYM is a systemic methodology with a robust mathematical and semantic understructure capable of effectively guiding multi-agent dialectic design processes concerning boundary critiques, structures, procedures and interventions. The central concept in the application of DCSYM is the identification of the real problem through a systemic approach. That was our main aim in selecting this methodology in order to understand our system (the Department of Immunology-Histocompatibility of "Aghia Sophia" Children's Hospital), its external environment (the main hospital, other hospitals, paediatricians, partners, collaborating organizations and societies and others), the communication layers among its element and in relation to the environment, as well as the control existed.



Results: The methodology assisted us in understanding systemically the Center's internal, operating and external environment and revealed the communication problems that either delay or affect negatively the process of registering PID patients.