

Module 3: Working family-centred in the context of cardio-genetics December 8th 2020 12:00-02:00 pm	
Theme: family-centric approach	Multidisciplinary family-centred psychosocial care for patients with CHD: data on patient-reported outcome-measures in adults with congenital heart disease Objective: Illustration of psychosocial guidelines and indications in both acquired and congenital heart disease
12:00-12:10	Introduction: Saar Van Pottelberghe-PhD
Presentation of the summary <u>discussion Module 2</u>	By developing a Patient Reported Outcome Measure (PROM) aiming to enhance counselees' realistic expectations and participation during genetic counselling, we empower patients. Patient self-care also entails coping with emotional distress. The more empowered patients are, the more likely they are to self-manage and actively seek advice.
12:10-12:30	dr. Edward Callus , patient representative and president of the European Congenital Heart Disease Organisation, also a research fellow at the Università degli Studi di Milano and head of the clinical psychology service at the IRCCS Policlinico San Donato specialized in both acquired and congenital heart disease
Objectives: * Illustrations of PROMS and constructs in conHD * Suggestion of Organizational aspects when it comes to delivery of psychosocial care in healthcare * Differentiation of peer to peer support and psychology services – with a specific example in Italy * Description of CHD and conHD psychosocial guidelines	Psychosocial care is not mandatory and sometimes not even considered in many health settings even though patients and families request it, and scientific evidence suggests it is beneficial for both families and health care providers. The objective of this workshop is to suggest how and in what way psychosocial care can be integrated in the patient pathway on inherited cardiovascular disease (ICVD) and how to proceed with the inclusion of patient representatives in guidelines, by illustrating the example of acquired (CHD) and congenital heart disease (conHD). APPROACH-IS, the world biggest study using PROMS on adults with conHD will be briefly illustrated. The organization of psychosocial care (both through clinical psychology services and non-profit organisations) will be described. In conclusion the available psychosocial recommendations of both disease categories will be presented
12:30-01:20	Break-out rooms for sharing & brainstorming on topic of today
In subgroups We will ask one participant to take notes and present the results (later)	Further inventory of actual social care pathways applied in different centres. Further inventory of needs of patients. What are the guidelines that are followed? What is the follow-up of patients?
01:20-01:30	Break with virtual cookies
01:30-01:55	Presentation of discussion and results in the subgroups to the entire group
One person per group represents results from discussion	What are the major findings, beliefs, attitudes? What sounded familiar and what was new to you?
01:55-02:00	Wrap up. Preparation for next session.