

Module 2: Working patient-centred in the context of cardio-genetic November 17 th 2020 3:00-5:00 pm	
Theme: Patient centric approach.	What are the needs of patients with <u>inherited cardiovascular disease</u> ?
03:00-03:10	Introduction: Saar Van Pottelberghe-PhD
Presentation of the summary <u>discussion Module 1</u>	Patient-centred care is widely recognised as a core dimension of a quality modern health service (Queensland Health, 2017). The information gathered from PROMs help to improve and focus patient-centred clinical management (Kingsley & Patel, 2017). 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.
03:10-03:30 and chair of the	MD Ruth Biller, chair of the German patient organisation ARVC-Selbsthilfe e.V. European patient advocacy group of ERN GUARD-Heart
Objectives: * Identification of unmet patient needs * Self-reflection (what can be improved in my department?) * Considerations for improved patient care at the time of diagnosis	Clinical patient pathways are focused on medical factors to ensure a correct diagnosis is established. When patients are confronted with the diagnosis of inherited cardiovascular disease, they need more than just medical information. They are suddenly catapulted into a reality in which they have to face many medical and psychosocial difficulties, which impact all areas of their lives and their relationships. That is why patients who are confronted with the diagnosis need doctors who take time for communicating, the possibility to refer to the same person for follow-up and the availability of psychological support which should be provided or at least offered immediately upon diagnosis, and again after a certain period of time when patients and relatives have grasped the full implications of the diagnosis. An example of an "ARVC patient journey" (ARVC = arrhythmogenic right ventricular cardiomyopathy) with reference to the cross-border patient pathway provided by ERN GUARD-Heart will highlight the patients' concerns which are not considered in the clinical pathway. Results from a survey on patient needs when confronted with the diagnosis ARVC, which was created by the national German non-profit organisation ARVC-Selbsthilfe e.V., will be presented, confirming that many of the patients felt that their needs were unmet.
03:30-04:00	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?
04:00-04:10	Break with virtual cookies
04:10-04:45	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?
04:45-05:00	Wrap up. Preparation for next session.