

Workshop PROMS & PREMS organization:
Working patient-centred in the context of cardio-genetics

- Online module
 - 4 modules of 2 hours (29th of October 2020, 17th of November 2020, 8th of December 2020, 12th of January 2021)
 - Over the course of 1 or 2 months
 - Start
- Start October 29th 2020 with guest speaker professor Nina Kupper
- Break-out rooms (>10 participants) for sharing & brainstorming
 - In the break-out room a person is selected to moderate the group.
 - Ruth, Edward, Nina and Saar participate in these groups.
 - Work on comparison of the different conditions that exist now.
 - Aim: starting specific guidelines within cardio-genetics
- Wrap up by sharing results with the entire group
- Preparation for next session
- Module 1 & 2:
 - Presentation of results of online survey: Saar Van Pottelberghe-PhD
 - 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.
 - Further inventory of actual social care pathways applied in different centres

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1. Module 1: October 29th 2020
10.00 -12:00 am

Theme: Health-care professional centric.

Objective: What are the tools health care professionals use in cardio-genetics to measure patients' psycho-social needs?

Speaker: Prof.dr. Nina Kupper, PhD, Associate Professor, Head of the Behavioral Physiology Lab (GO-LAB), Department of Medical & Clinical Psychology, Center of Research on Psychology in Somatic Diseases, Tilburg University, Tilburg, The Netherlands

In order to organize the delivery of clinical care around the needs of the patient, we must understand what those needs are, and identify areas where disconnects exist that impair the satisfaction of those needs. Routine patient-reported outcome (PRO) measurement for psychosocial outcomes is a necessary first step to identify the psychosocial needs of patients with heart disease. This presentation will show several examples of tools to assess PRO and recognizes the need to develop a disease-specific (i.e. cardio-genetic specific) PRO measure. A second aspect of empowering the patient in patient-centred care is to improve the process of information provision and shared-decision making. This presentation will discuss available tools to improve decision-making, and addresses the need for a more specialized tool for cardio-genetics.

Objectives:

- * Identifying gaps in the literature on PRO in cardio-genetics
- * PRO assessment in cardio-genetics: what would that look like

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2. Module 2: November 17th 2020
03.00-05.00 pm

Theme: Patient centric approach.

Objective: What are the needs of patients with inherited cardiovascular disease.

Speaker: Ruth Biller, chair of the German patient organisation ARVC-Selbsthilfe e.V.
and chair of the European patient advocacy group of ERN GUARD-Heart

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.

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

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3. Module 3: December 8th 2020 12.00-2:00 pm

Theme: family-centric approach

Objective: Illustration of psychosocial guidelines and indications in both acquired and congenital heart disease

Speaker: 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:

Multidisciplinary family-centred psychosocial care for patients with CHD: data on patient-reported outcome-measures in adults with congenital heart disease

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.

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