

<p>Module 1: Working patient-centred in the context of cardio-genetics Health-care professional centric October 29th 2020 10:00-12:00 am</p>	
<p>Theme: Health-care professional centric.</p>	<p>What do health-care workers think is the need of cardio-genetics patients? What are the tools health care professionals use in cardio-genetics to measure patients' psycho-social needs?</p>
<p>10:00-10:10 Introduction: Saar Van Pottelberghe-PhD</p>	
<p>Presentation of the <u>results of the online survey</u>:</p>	<p>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.</p>
<p>10:10-10:30 Speaker: Prof. dr. Nina Kupper</p>	
<p>Objectives: * Identifying gaps in the literature on PRO in cardio-genetics * PRO assessment in cardio-genetics: what would that look like</p>	<p><i>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 disconnections 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 psycho-social 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 provision of information 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.</i></p>
<p>10:30-11:00 Break-out rooms for sharing & brainstorming on topic of today</p>	
<p>In subgroups We will ask one participant to take notes and present the results (later)</p>	<p>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?</p>
<p>11:00-11:05 Break with virtual cookies</p>	
<p>11:05-11:45 Presentation of discussion and results in the subgroups to the entire group</p>	
<p>One person per group represents results from discussion</p>	<p>What are the major findings, beliefs, attitudes? What sounded familiar and what was new to you?</p>
<p>11:45-12:00 Wrap up. Preparation for next session.</p>	