

Module 4: Working family-centred in the context of cardio-genetics January 12th 2021 12:00-02:00 pm	
Theme: family-centric approach	formulate guidelines/recommendations for inherited cardiovascular diseases that will aid patients' decisional process in: Clinical diagnosis, genetic testing and diagnosis, treatment, rehabilitation
Objective:	Transforming recommendations from committee into specific cardio-genetics guidelines
12:00-12:30	Development and implementation of a Patient Reported Outcome Measure (PROM) in oncogenetics
<p><u>Prof.dr.Eveline Bleiker</u>, psychologist, Division of Psychosocial Research and Epidemiology of the Netherlands Cancer Institute, Amsterdam, and at the Department of Clinical genetics of the Leiden University Medical Center, Leiden, The Netherlands</p> <p>EB: The development of the 'Psychosocial Aspects of Hereditary Cancer (PAHC)' questionnaire</p>	<p><u>Dr. Margreet Ausems</u>, Clinical geneticist, Associate Professor and Principal Investigator, Division Laboratories, Pharmacy and Biomedical Genetics, Department of Genetics, University Medical Center Utrecht, The Netherlands</p> <p>MA: Implementation of the PAHC in daily practice</p>
Background of speakers	
<p>The aim of the work of <u>prof. dr. Eveline Bleiker</u> is to improve the quality of life and quality of care of individuals diagnosed with cancer and those at high risk of developing cancer. In her studies, three related research topics can be distinguished:</p> <ol style="list-style-type: none"> 1) Studies investigating the uptake and psychosocial impact of genetic counseling and testing for specific hereditary cancer syndromes, 2) Studies investigating decision making and cancer-risk reducing behavior among at-risk individuals, and the demographic, clinical, and psychosocial variables that may be associated with decisional conflict and (non) compliance with prevention recommendations, and 3) Studies aimed at understanding and improving quality of life and quality of care for individuals with (a high risk of developing) cancer. <p>The study designs vary from observational (uptake and impact studies), prospective follow-up studies (long-term surveillance studies) to randomized controlled trials (psychosocial intervention studies to improve quality of life and quality of care and to reduce symptoms like stress and fatigue). She was PI on the 4-year project on the development and testing of the 'Psychosocial Aspects of Hereditary Cancer (PAHC).</p>	<p><u>Dr. Ausems'</u> research has a focus on medical and psychosocial aspects of cancer genetic counseling in affected patients and their relatives, and on public health aspects of cancer genetic counseling (e.g. on how to improve the uptake). The research program fits in the Personalized Cancer Care priority program of the UMC Utrecht. In previous research needs and preferences of counselees in cancer genetic counseling were extensively studied. Based on these results, a web-based education for counselees (E-info gene) was developed enabling a better preparing for breast cancer genetic counseling. In 2012 Ausems and her team were awarded the 'Medisch Contact Communicatieprijs 2012' for the development of this web-based education tool for counselees referred for breast cancer genetic counselling. She is currently leading three national multi-center research projects on the development and implementation of new workflows in the clinic (mainstreaming of genetic testing) on a safe and ethical sound way. These projects aim to increase the uptake of genetic testing in cancer patients, and also tackle the current unequal access to genetic testing. The development of training modules for other referring clinicians (surgeons, gynecologists, medical oncologists and urologists) is a key component of these projects that include the set-up of new counseling pathways.</p> <p>Dr. Ausems has participated in the development and testing of the 'Psychosocial Aspects of Hereditary Cancer (PAHC)' questionnaire and she was involved in the implementation of this questionnaire in daily practice. At the department of Genetics, all newly referred patients for cancer genetic counseling are currently invited to complete the PAHC questionnaire before their first visit.</p>
12:30-01:20	Break-out rooms for sharing & brainstorming on topic of today
01:20-01:30	Break with virtual cookies
01:30-01:55	Presentation of discussion and results in the subgroups to the entire group
01:55-02:00	Wrap up. What will come out of this?

