Background A family-centered pediatric ACP intervention (FACE) was developed in the US, which demonstrated feasibility, acceptability and safety. The aim of this study is to evaluate the effectiveness of an ACP intervention, adapted from the FACE intervention, for pediatric oncology in Flanders, Belgium.

Methods A total of 93 dyads of parents and adolescents (age 10 – 18) receiving care in pediatric oncology wards will be recruited. Intervention dyads (N=46) will receive three weekly 60-minute sessions. Control dyads (N=46) will receive care as usual. Primary outcome is congruence in treatment preferences between adolescent and parent, measured by the Statement of Treatment Preference. Secondary outcomes: quality of communication, decisional conflict for adolescents, and quality of life of adolescents and parents. Outcomes will be measured at baseline (T0) and 3 months after the intervention (T1). A process evaluation will be done by documentation of recruitment, analyzing audio recordings of the intervention, and post-trial qualitative interviews with adolescents (n=10) and parents (n=10) and focus groups with the involved healthcare professionals.

Discussion This will be the first pACP intervention in Europe and will provide evidence on the effectiveness of an ACP intervention in adolescents with cancer. A process evaluation will provide in-depth insight into how the pACP intervention was delivered in practice and contribute to understanding the underlying mechanisms of the intervention.

Methods An interpretative qualitative study using thematic analysis was performed. Single interviews were undertaken with 17 pediatricians working in five pediatric tertiary hospitals.

Results Initiation of ACP discussions is determined by expected disease progression, technical treatment options or increasing symptoms. Pediatricians prefer to discuss ACP within a long-term relationship with a child’s family. This ensures and enables them to address issues concerning challenging medical decisions and end-of-life in the right way at the right time for a specific family. Pediatricians focus in ACP discussions on future scenario’s and related care options. They try to balance between ‘hope’ (normalizing living with illness, focus on problem solving) and ‘the worst’ (decline of the child’s condition and an inevitable death). They aim to prepare the child and family for ‘a life as normal a possible and when inevitable, a good end of life’. Few pediatricians explore the child’s and family’s values and perspectives.

Conclusion Pediatricians focus on prognosis and treatment options in ACP conversations. They take families by the hand throughout the disease trajectories and try to guide medical decision making in the best interest of the child. Exploration and integration of family values seems less integrated in their practice.

Background Parents of adolescents with a life-limiting illness have expressed the desire to talk to their children about goals and preferences of care. Recently, a family-centered pediatric advance care planning (ACP) intervention (FACE) was developed in the US, which demonstrated feasibility, acceptability and safety. The aim of this project is to develop a pediatric ACP (pACP) intervention by translating the existing FACE intervention and adapting it to the Belgian situation for pediatric oncology wards through semi-structured interviews. Second, four separate focus groups with the abovementioned groups will be organized. Third, experts with extensive experience in ACP with children will review the materials individually and findings will be discussed in an expert panel. Before pilot testing the intervention, cognitive testing of all questionnaires used for the outcome measurements with adolescents, their parent (n=4) and physicians (n=4) will be done. All retrieved information will be processed in a first version of a manual of how the intervention is delivered.

Discussion After development of the pACP intervention, effectiveness will be tested in a randomized controlled trial design. Primary objective of the trial is to assess whether the pACP intervention improves congruence in treatment preferences.