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Background: Up to 90% of children diagnosed with a chronic disease need continuous medical care during adulthood. Pediatric and adult healthcare settings significantly differ from each other. In addition to changing care team, the adolescent and young adult (AYAs) needs to assume responsibility for managing their illness in daily life, which had been mainly done by the parents. These changes take place during adolescence, one of most difficult phases in life. In addition to the normal challenges of being a teenager, AYAs suffering from chronic disease(s) have to deal with disease related issues (e.g. physical and/or mental disabilities). An inadequate transition can have serious negative consequences. A well-planned transition built on an individual, structured management plan is therefore crucial for successful transition to adult healthcare.

Rheumatological diseases are common chronic diseases diagnosed during childhood. A recent study assessing current transitional care (TC) practice in all 10 pediatric and their collaborating adult Swiss rheumatology centers, showed large variability between the centers and that many TC recommendations were not implemented.

Purpose: Therefore, the purpose of the rHEumatology tRansition for yOung pEople in Switzerland (HEROES) study is to develop, implement and evaluate a rheumatology TC program to optimize care for AYAs moving from pediatric to adult settings in Switzerland. The aims are to: assess AYAs' and parents' experiences related to current TC practices; to assess stakeholders and healthcare professionals' barriers and facilitators (e.g. acceptability, feasibility, appropriateness) for implementing a TC program; develop and implement a TC program; assess implementation outcomes (adoption, fidelity, penetration and sustainability) of the program; and evaluate its effectiveness in relation to disease-related outcomes, AYAs- and parent- and healthcare professional-reported outcomes and care experiences, and economic outcomes.

Design: In order to ensure successful development, implementation and sustainability of the intervention, this study will use a hybrid-effectiveness implementation type 2 design. A participatory partnership approach will be used.

Setting, sample: All 10 Swiss pediatric rheumatology centers and their adult counterpart agreed to participate in the study, representing all Swiss language regions. For the different aims of the study, different samples will be used: AYAs and parents to assess experiences with current TC practices and to assess innovation outcomes (control and intervention group); stakeholders from each center (to assess implementation antecedents: barriers, facilitators and readiness to implement a TC program), and professionals involved in intervention delivery (e.g. to assess the implementation outcome antecedents and implementation outcomes).

Intervention development will be based on a taxonomy of O’Cathain et al. which consists of a 7-step (conception, planning, designing, creating, refining, documenting and planning for future evaluation) approach including 18 actions to develop an intervention.

Variables, measurement, data collection: Acceptability, appropriateness and organizational implementation readiness will be measured in each center prior to intervention implementation. *Implementation outcome* will be measured in each center after implementation. *The innovation (intervention) outcomes* will be measured at the AYA level (e.g. quality of life, medication and appointment adherence) and parent level (e.g. satisfaction with TC, trust in the healthcare team) Economic outcomes will be measured at the AYA, parent, healthcare system and societal levels. A variety of methods will be used to collect data, including self-report questionnaires, chart review, logbooks, focus group and individual interviews.

Data analysis: Qualitative data will be analyzed according to Braun and Clarke’s thematic analysis approach. Quantitative data will be analyzed using descriptive statistics, independent sample t-tests or Mann Whitney U tests, and repeated measures models. Costs and cost-consequence analysis will be used to analyze economic outcomes.