Supplementary material 1
Research Program Overview

Theoretical framework: UK Medical Research Council Complex Interventions (1,2)

11 participating pediatric metabolic disease centres across Canada

Study 1
QUANT + QUAL study of health care experiences from the perspectives of parents of children with inherited metabolic diseases

Study 2
QUAL interview study of health care providers about barriers and facilitators of family-centred care

Study 3
LIT REVIEW of family-centred care interventions for children with ongoing health needs

Study 4
Development of interventions and evaluation framework of interventions

Full engagement of patients and families
REFERENCES
