Due to more effective treatment protocols, seventy percent of patients with childhood cancer in the Netherlands nowadays have a five years survival. Long term follow up, however, shows that these treatment protocols leave seventy to eighty percent of these patients with adverse outcomes. Preserving treatment details and data on adverse long term treatment effects is invaluable for individual patient care and clinical research. Further care of these patients requires detailed information on previous exposure to radio- and chemotherapy, bone marrow transplantation and chirurgical treatment. Research on adverse long term risks of these treatments is important in evaluating treatment protocols and planning future treatments of these patients. Several cohort and case control studies on long term treatment effects of childhood cancer have been completed. Yet, these studies were based on reviewing paper based medical records and medical notes relating to treatment details. Besides premature destruction of these records, details of therapy are often lost because of inadequate archiving by clerical staff with little knowledge of which aspects of these paper based records are most important in terms of long term care and research needs. Usage of these paper based records has therefore greatly limited these studies. Also, the follow-up period of patients with childhood cancer has been too short to conclude that all late adverse treatment effects are known. Outcomes research on these treatment effects has thus been fragmentary and incomplete. Besides, due to the multidisciplinary character of these long term treatment effects, the screening and possible treatment of these adverse effects is a task of increasing complexity which requires the cooperation of a variety of medical and paramedical disciplines. Computer based clinical record systems can support this screening process by providing computerized screening forms used for data capturing, report facilities used for individual patient management and applications that report relevant subsets of the patient database information in a variety of formats. We have developed such a computerized patient record system (PLEK-sys) for evaluation of late treatment effects of childhood cancer that circumvents many of the problems of paper based record usage in research and that provides valuable functions impossible with a paper medical chart. PLEK-sys is a multi function patient record system that maintains all the patient data generated during the screening encounters. A user-friendly interface has been designed in collaboration with the end users; the clinicians. Data are stored in a relational database management system, using entity relationship diagram method for designing the database. Various overviews and reports of the data may be generated, ranging from individual patient to patient cohort overviews. For more complicated searches, a ‘custom search editor’ may be invoked by which users can create complicated queries of which the results are displayed graphically. Complicated search steps can be stored as a template for repeated future overviews. Graphical display of patient data is supported by a graphical module. Detail information on the functions and services which were implemented in PLEK-sys will be presented at the conference.

References