remote data-entry (RDE) system based on flexible XML-based technologies for the registration of follow-up data within our Late Effects Surveillance System. The Late Effects Surveillance System (LESS) registers late effects in relapse-free Ewing’s-, soft tissue- or osteosarcoma patients treated within the EICESS-92/EURO-E.W.I.N.G-99, CWS-96/CWS-2002 and COSS-96 therapy optimization trials, respectively, in Germany, Austria and Switzerland.

Method: 2,856 registered former patients with 41,000 paper-based query forms were available in a legacy LESS database (which did not yet support remote data-entry). The registered patients were followed-up in 246 paediatric, internal medicine or other hospitals and 60 general practitioners and paediatricians which did not always have trained personnel available for data-entry, leading to heterogeneous data quality. Thus, a data migration concept was established by analyzing the legacy system and its data-entry forms and mapping the forms to corresponding ones in the new system. Afterwards a transformation of relational legacy data to XML-based data was conducted.

Results: Transition from a paper-based query system to an electronic, cost-efficient remote data-entry system based on XML was successfully pursued. Using XML technologies allowed the flexible definition of data-entry forms by physicians themselves. Data inconsistencies of the legacy system were identified and eliminated.

Conclusion: Through utilization of innovative programming concepts it is possible to eliminate the need for paper-based queries in large multinational clinical studies with heterogeneous contributing institutions, without the need for costly software licences for all study participants and with significant reduction of costs for data-entry, while simultaneously improving data quality and reusability.

L013

PSYCHOSOCIAL AND FUNCTIONAL OUTCOME IN LONG-TERM SURVivors OF OS TeOSARCOma: A COMPARISoN BETWEEN LIMb SALVAGE AND AMPUTATION

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Purpose: The purpose of this study was to compare the psychosocial and functional outcomes of osteosarcoma survivors who have limb salvage or amputation.

Traditional opinion has been that limb-salvage surgery would provide functional and cosmetic advantage over amputation, yet the literature has been equivocal for long term survivors. We hoped to contribute to the literature by utilizing a comprehensive set of validated psychosocial and functional outcome measures.

Method: Participants were

Results: Fifty-seven survivors participated, including 35 with limb salvage and 22 with amputation. Participants were 12 to 24 years post-diagnosis and 16 to 52 years of age at the time of this evaluation. Chi-square tests of independence revealed no comparative group differences in patient characteristics, including age at time of study participation, age at diagnosis, and time since diagnosis. Multiple linear regression models were used to examine differences in quality of life, body image, self-esteem, and social support between the two patient groups. No comparative group differences were found. Lower limb function was a significant predictor of quality of life (p < 0.001), and neither time since diagnosis nor surgery type impacted this relationship (p < 0.001). Upper limb function was not related to quality of life.

Conclusion: Participants with more functional lower limbs reported better quality of life, regardless of whether the participant had an amputation or a limb salvage and regardless of time since diagnosis.

L014

PROSPECTIVE EVALUATION OF ANTIENOPLASTIC THERAPY SEQUELAE IN SARCOma PATIENTS AFTER HIGH-DOSE CHEMOTHERAPY WITH STEM-CELL RESCUE

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Purpose: There has been concern that growth hormone (GH) replacement might increase the risk of tumour recurrence in childhood craniohypophysiyngioma. In our prospective trial KRANIOPHARYNGEOM 2000 we analyzed the impact of GH on relapse rates.

Method: Between 2001 and 2006 117 patients with childhood craniohypophysiyngioma were recruited with a median age of 10.0 years at diagnosis. Histology and imaging were prospectively assessed by a reference panel. The impact of gender, age at diagnosis, degree of resection, GH treatment and age at initiation of GH-treatment on progression and relapse rates could be analyzed in 108 of 117 patients by multivariate analyses. GH treatment was initiated at a median time of 0.8 years after diagnosis (n = 54). 24 patients (46%) received GH after CR, 29 patients after IR.

Results: We observed a 3-1/2-year event-free survival (EFS) of 0.45 ± 1.06, indicating high recurrence rates after complete resection (CR) (n = 47; 3-1/2- EFS: 0.63 ± 0.09) and high progression rates after incomplete resection (IR) (n = 63; 3-1/2- EFS: 0.30 ± 0.07). In multivariate analyses, patients had a 72.5% lower risk of a first event after CR when compared with patients after IR (HR:0.277). Higher age at diagnosis had protective effects on EFS. The risk of an event decreased by 9.2% per year of age at diagnosis. The effect of GH on EFS was dependent on age at tumour diagnosis. The risk of an event under GH was 6 times increased (HR: 0.335), but it decreased by 27.6% per year.