

# Assessing quality of life in sarkoma trials

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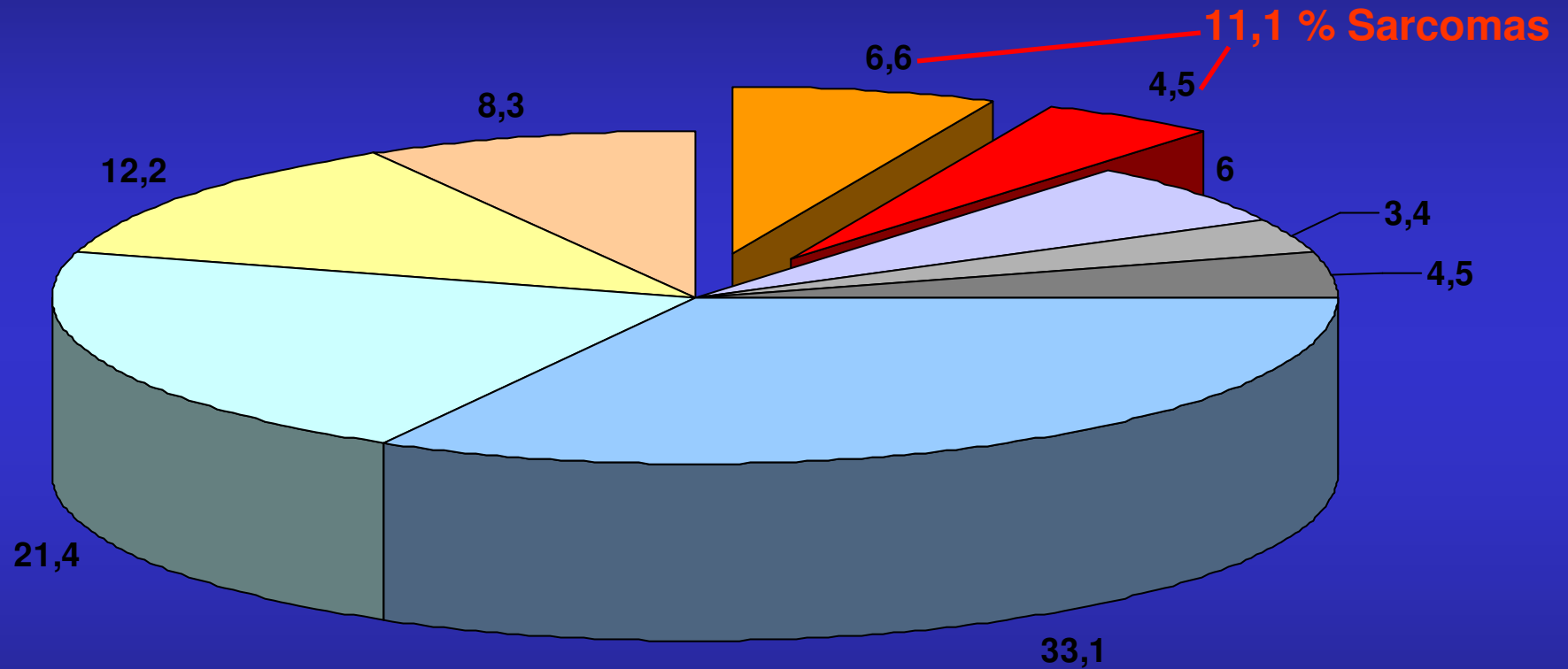
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Westfälische  
Wilhelms-Universität  
Münster



# Frequency of sarcoma



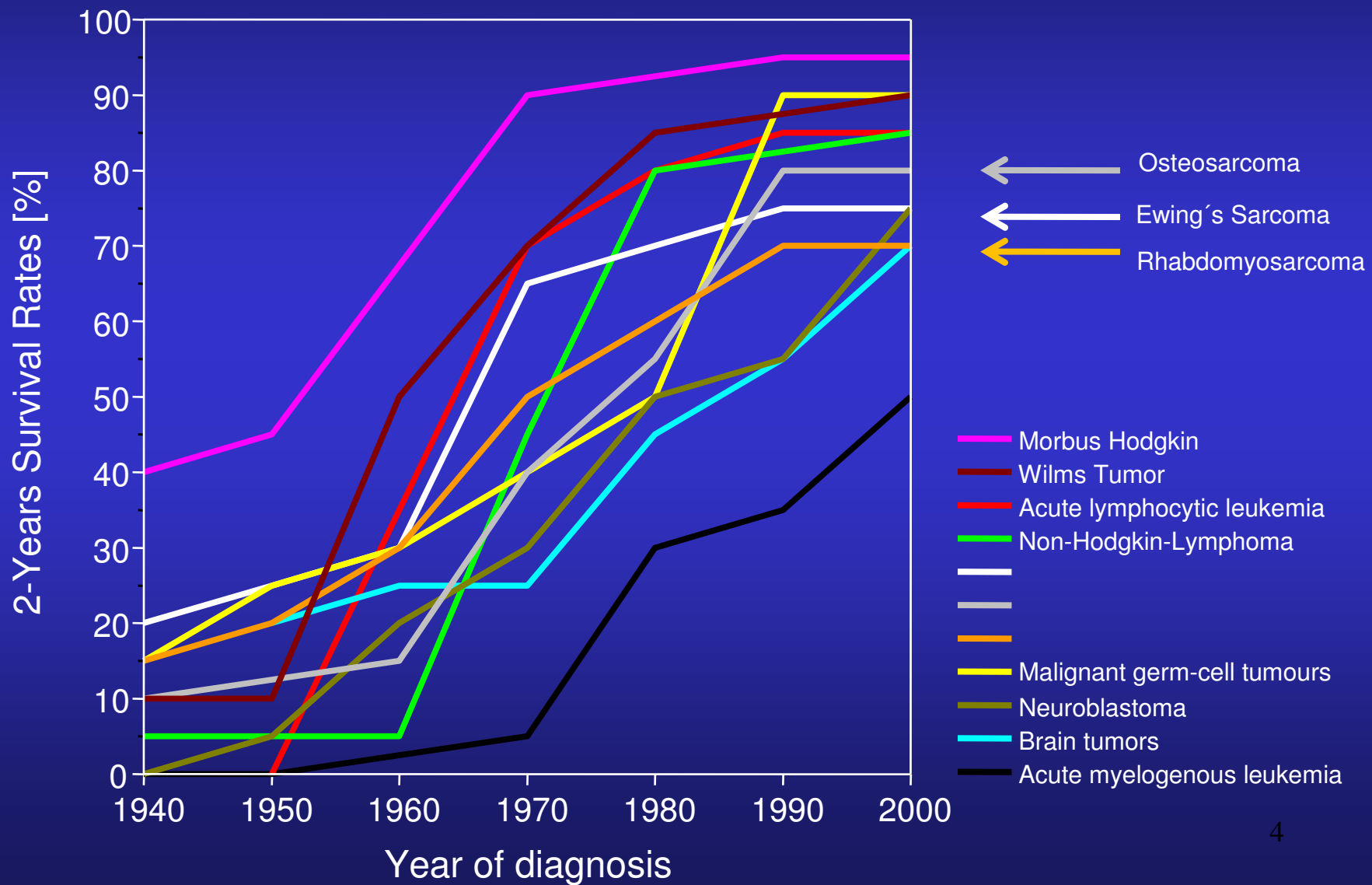
- soft tissue sarcomas
- renal tumours
- other diagnosis
- CNS tumours
- Sympathetic nervous system tumours
- bone tumours
- Germ cell tumours
- Leukaemias
- Lymphomas

\* Kaatsch et al. :Annual Report 2005 German Childhood Cancer Registry

# **Treating children with cancer**

**Survival is the goal**

# Development of Survival Rates



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# **1. The goal of cure and care of childhood cancer**

The long-term goal of the cure and care of the child with cancer is that he/she become a resilient, fully functioning, autonomous adult with an optimal health-related quality of life, accepted in the society at the same level of his/her age peers.

# What is Quality of Life?

- **the individual perspective in respect to aims, expectations, possibilities influenced by cultural environment.**
- **it contains but is not limited to social, emotional and physical capacities of the child / adolescent and his family**
- **it has to be viewed from the perspective of the child / adolescent and the family and should include developmental changes**

**Bradlyn, 1995**

## Child

outward appearance  
(nice hair)

physical activity  
(to run, climb, play ...)

friends

## Adolescent

friends,  
body image,  
outward appearance,  
self dependency,  
professional  
training

## Young adult

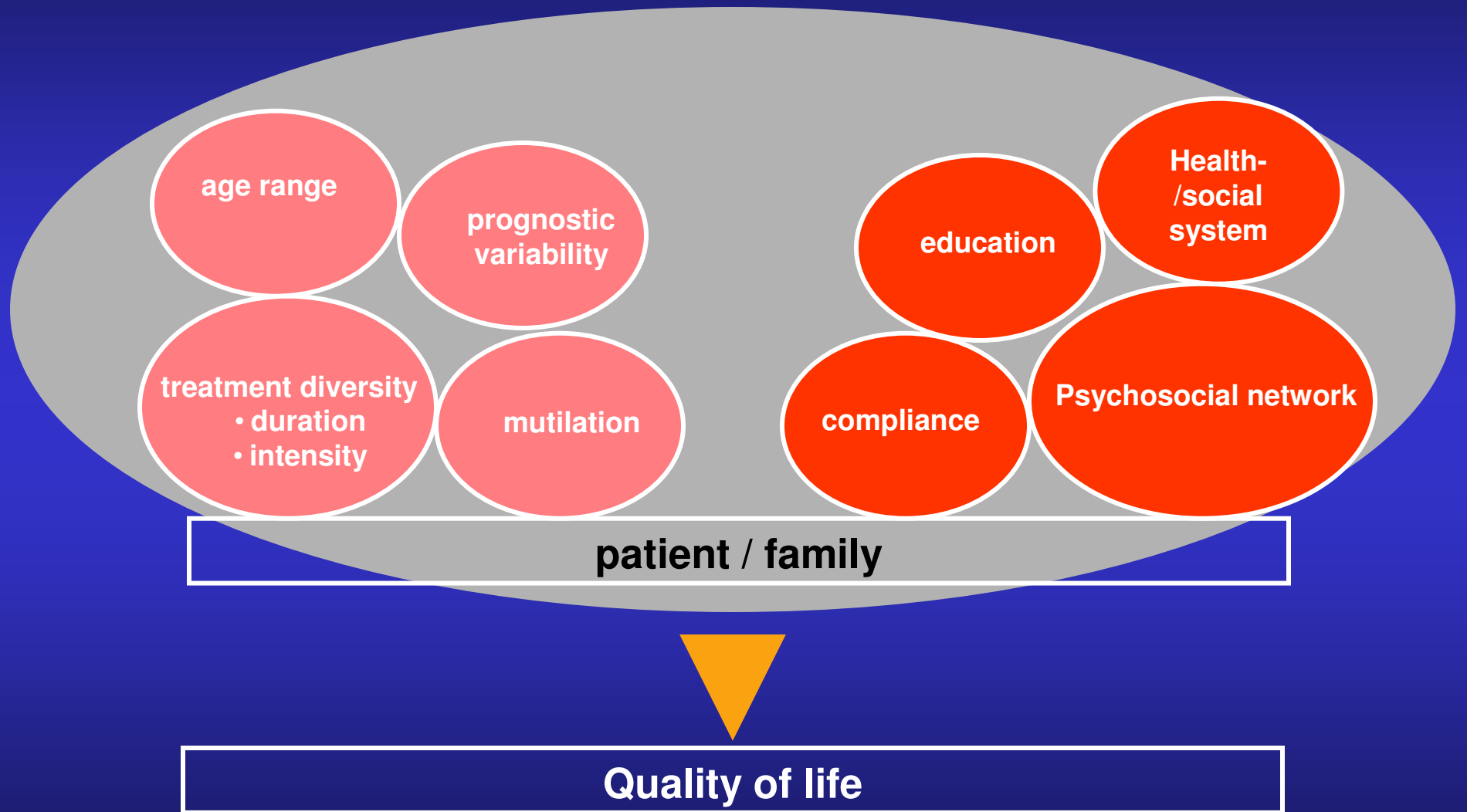
Autonomy

(income, to live independent)

professional training,  
job

steady partnership

# Factors influencing QoL



# Measuring QoL

Why ...

How ...

Analysis

Interpretation

Timing ...

Logistics ...

# Measuring QoL: Why ?

# QoL data

**provide additional information**

- **to compare treatment strategies**
- **Additional information to survival data**
- **detection of changes in psychosocial functioning**
- **value of physical and psychosocial rehabilitation**
- **value of palliative care**

# Measuring QoL: How ?

- **Interviews**

Limitations: data security, staff, time consuming

- **self / proxy report Questionnaires**

Limitations: different view on QoL and problems

- **self reporting  $\geq 8$  years**

Limitations: age, ability to understand things

# Analysis

Evaluation of scores for different domains and correlation to Norm Groups

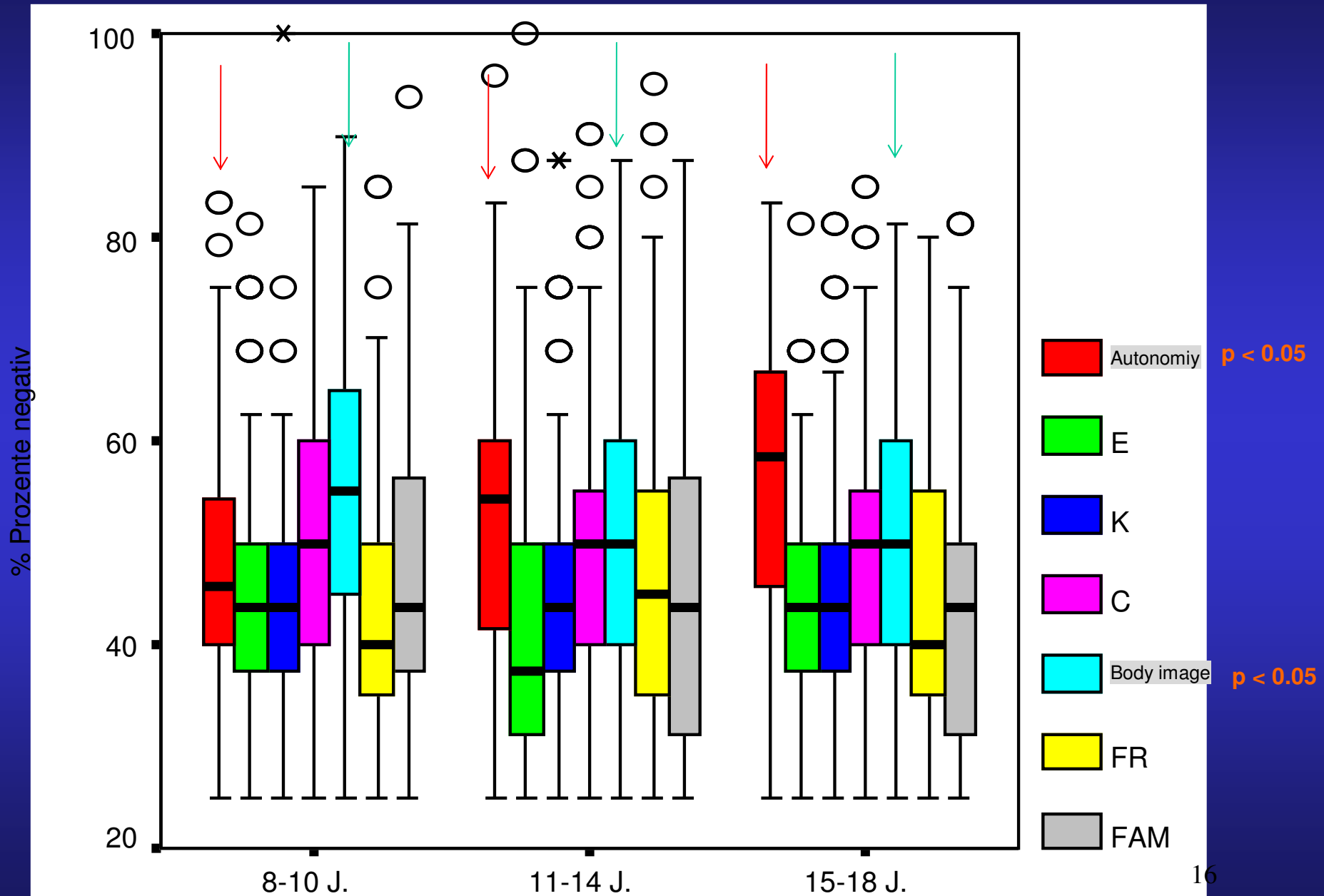
- Age and sex

Significant differences (negative/positive)

- Over time (E1 → E2 → E3 same treatment)
- At one time point between treatment arms

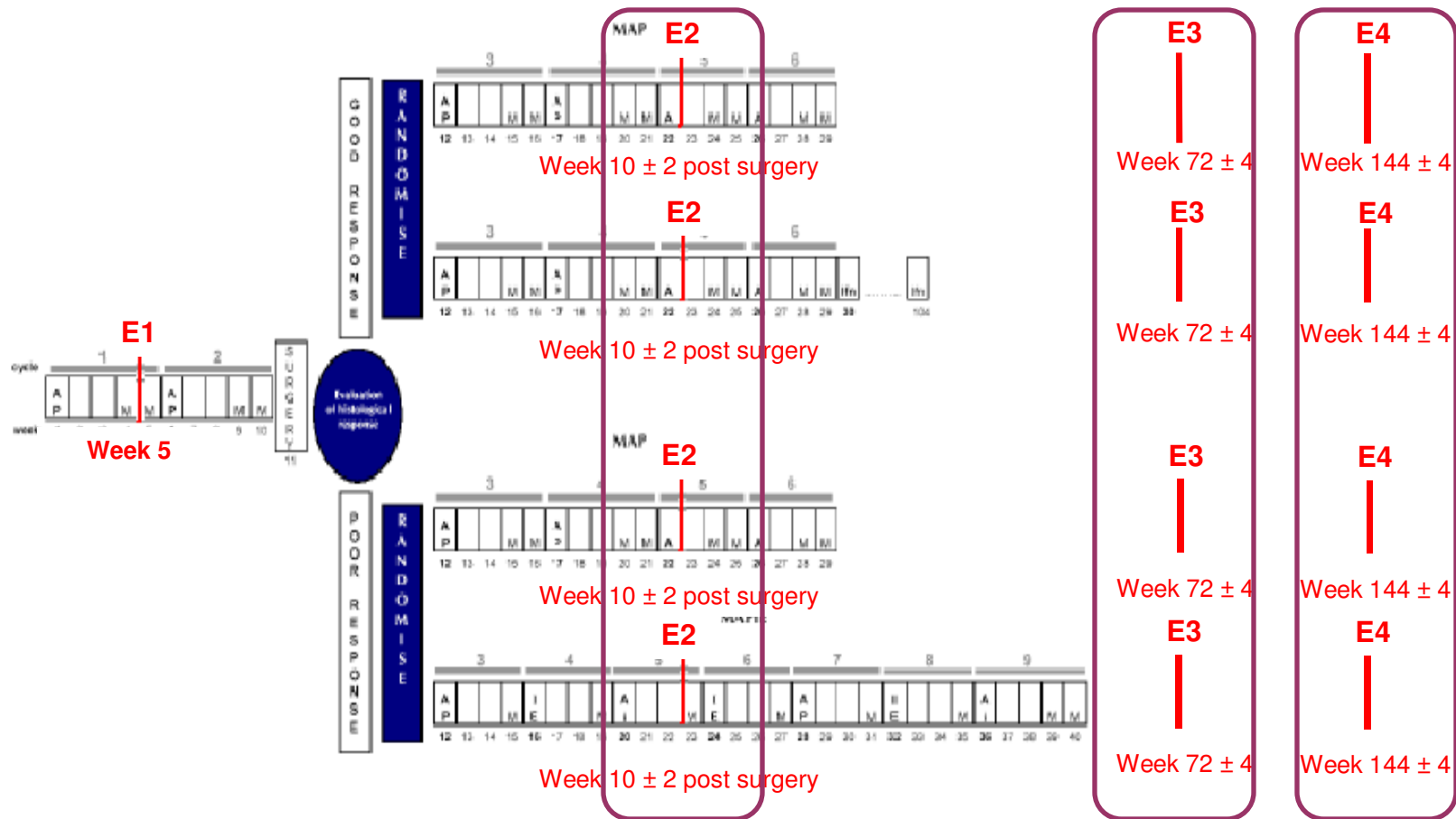
# Examples

# Quality of Life in schoolchildren n=1200





# Cross sectional comparison of QoL data



# Interpretation

- Correlation to Norm Groups  
Age and sex
- Correlation to treatment  
Surgery, chemo, RT
- Correlation to somatic data  
toxicity, functional abilities

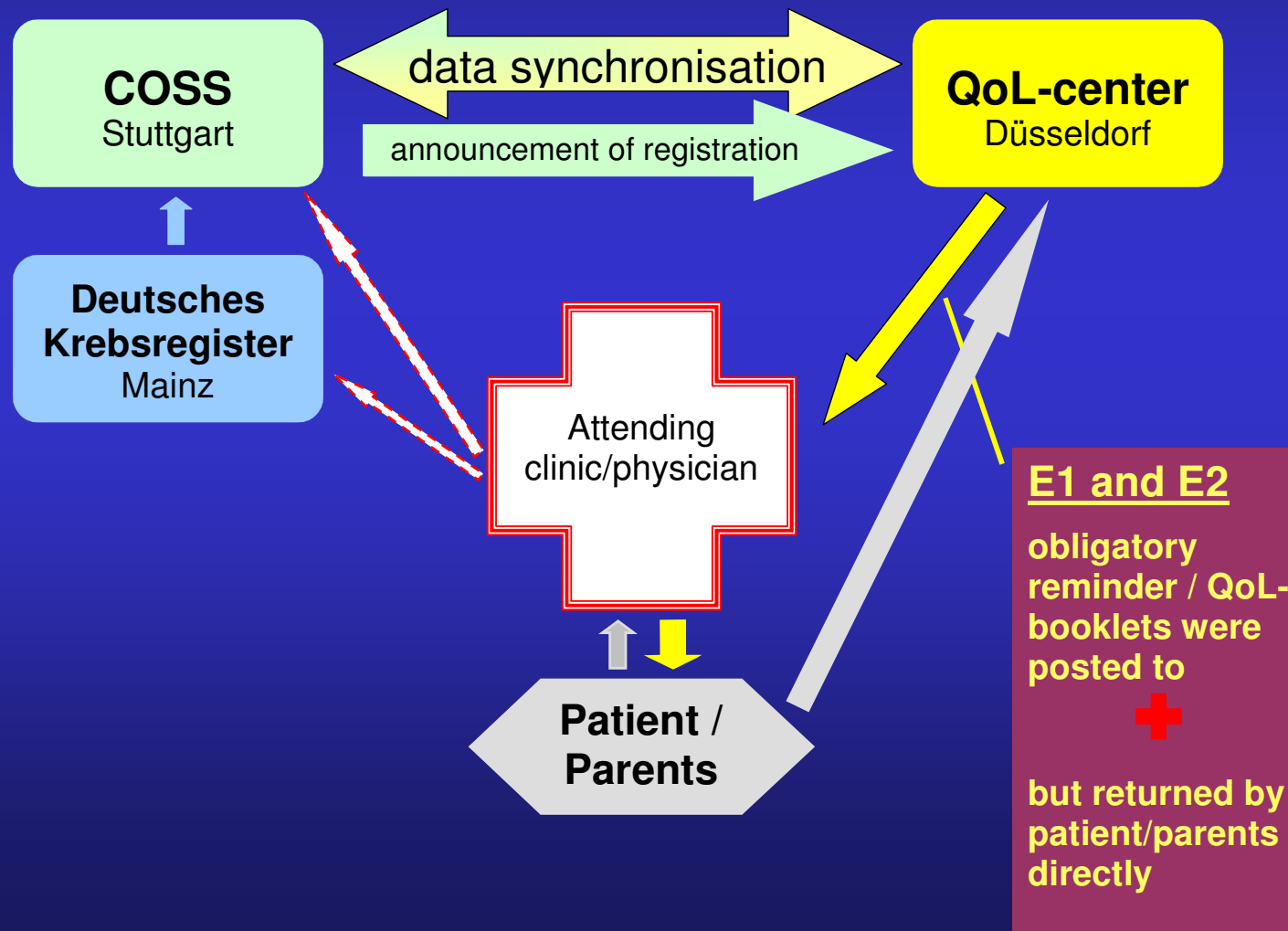
# Timing

- Intervals between evaluation > 6 weeks
- Time window not too short
- Instruments easy assessable
- Reminder system effective

# Logistics

# Flow of QoL information / data in Germany

## E1 / E2



# Sarcoma

What do we know about QoL ?

# Ewing and osteosarcoma

## Education, Employment, Insurance, and Marital Status among 694 Survivors of Pediatric Lower Extremity Bone Tumors

*A Report from the Childhood Cancer Survivor Study*

CANCER May 15, 2003 / Volume 97 / Number 10

Rajaram Nagarajan, M.D., M.S.<sup>1</sup>

Joseph P. Neglia, M.D., M.P.H.<sup>2</sup>

Denis R. Clohisy, M.D.<sup>3</sup>

Yutaka Yasui, Ph.D.<sup>4</sup>

Mark Greenberg, M.D.<sup>5</sup>

Melissa Hudson, M.D.<sup>6</sup>

Michael A. Zevon, Ph.D.<sup>7</sup>

Jean M. Tersak, M.D.<sup>8</sup>

Arthur Ablin, M.D.<sup>9</sup>

Leslie L. Robison, Ph.D.<sup>1</sup>

- schooling/vocational training is of high importance in terms of successful long-term rehabilitation.
- This enables accessible employment, security and the ability to build up own family structures
- No difference for amputees and non-amputees

## BRIEF REPORT

### Quality of Life of Patients Treated During Childhood for a Bone Tumor: Assessment by the Child Health Questionnaire

Marie-Dominique Tabone, MD,<sup>1\*</sup> Chantal Rodary, MD,<sup>2</sup> Odile Oberlin, MD,<sup>3</sup> Jean-Claude Gentet, MD,<sup>4</sup>  
Hélène Pacquement, MD,<sup>5</sup> and Chantal Kalifa, MD<sup>3</sup>

- At assessment median age was 15 years,
- Mean scores were 60, 81, 76, 74, 70, 87 for general health, physical functioning, pain, mental health, self-esteem, family activity
- Lower results were observed for mental health in girls, for physical functioning, and self-esteem in patients with endoprosthesis,
- for family activity and pain in patients who had relapsed.

# Published studies

Quality of Life Research (2006) 15:1439–1446  
DOI 10.1007/s11136-006-0001-4

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## Evaluating function and health related quality of life in patients treated for extremity soft tissue sarcoma

Daphne Schreiber<sup>1</sup>, Robert S. Bell<sup>2,3,4,5</sup>, Jay S. Wunder<sup>2,4</sup>, Brian O'Sullivan<sup>4,6</sup>, Robert Turcotte<sup>7</sup>, Bassam A. Masri<sup>8</sup> & Aileen M. Davis<sup>1,4,9</sup>

The main impact on QoL has the ability to participate in normal life roles:

- get and maintain employment
- have a family and care for it
- participate in recreational activities

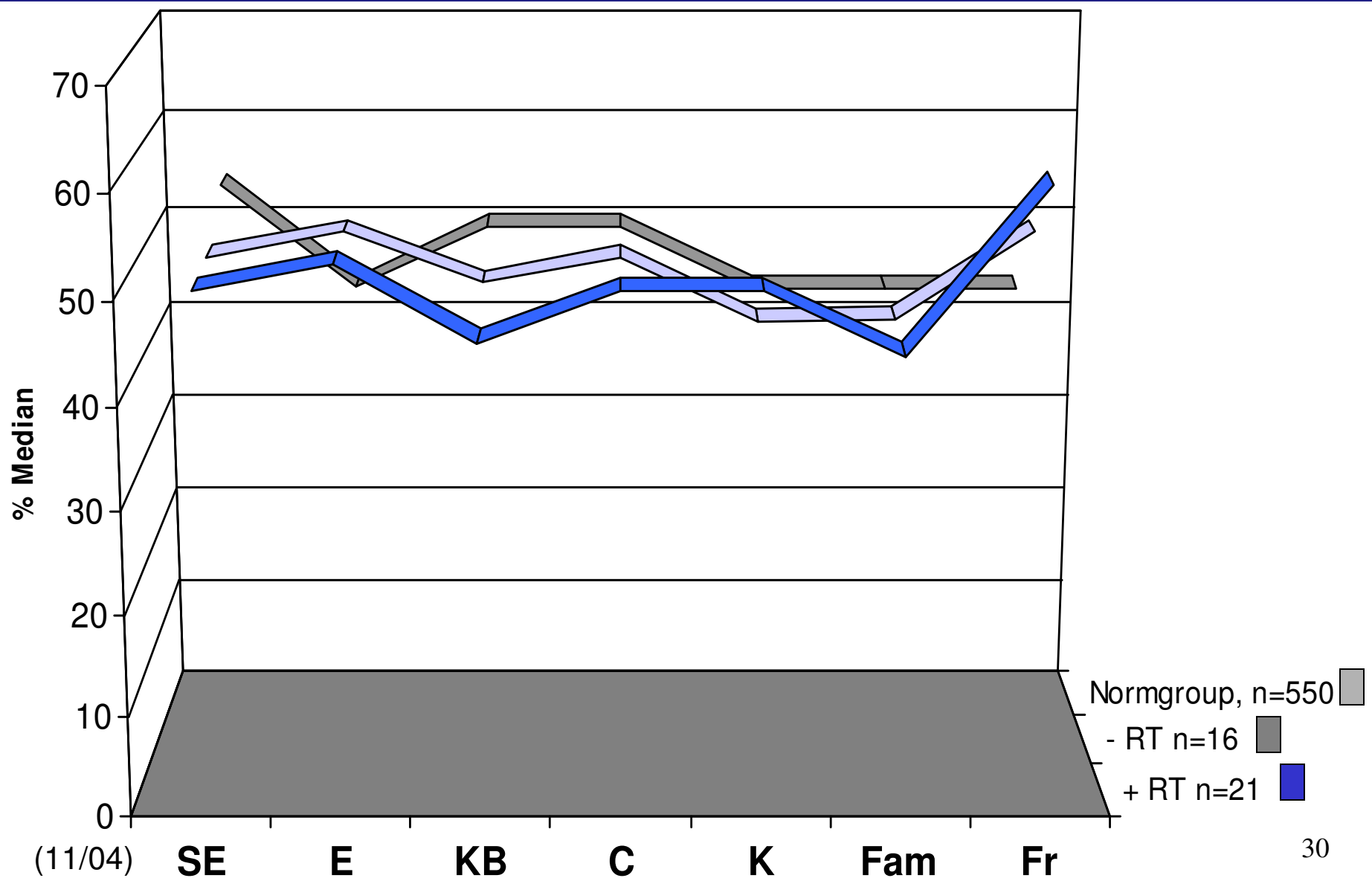
# Clinical Outcome and QoL?

# Examples

# Craniopharyngeoma

**impact of RT after incomplete resection**

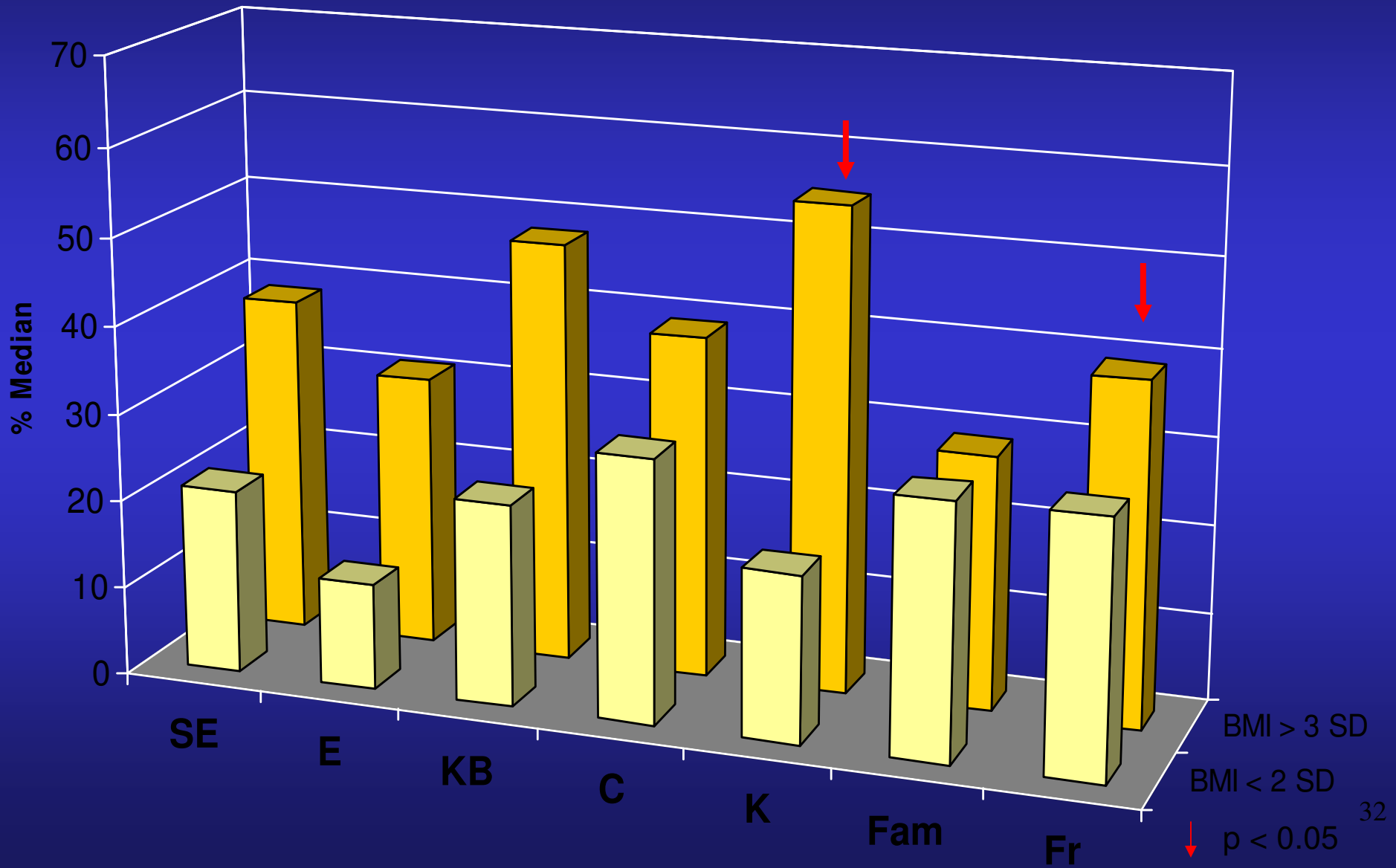
# +/- RT do not implicate a difference in QoL in patients with incompletely resected craniopharangeoma > 2 years after the end of treatment



# **obesity in Craniopharngioma**

**2 years after Dx**

# Obese Craniopharyngeoma pts ■ rate their QoL more negative than non-obese pts ■



# Cross sectional / longitudinal QoL study

(prospective, multicenter) Example:

## COSS/EURAMOS 1

Investigation of *Quality of Life* (QoL) in  
young patients with Osteosarkoma

(as one secondary end of the trial)

Trial opening in Germany 04/2005

# COSS/EURAMOS 1

## problems of interest

1. How do young patients with Osteosarkoma appraise their QoL?
2. Is there a difference in QoL between good and poor responders? (cross sectional comparison)
3. Does the additional application of interferon-alpha affect the QoL in patients with good prognosis?
4. Is the QoL affected in patients with poor responding and more intensive therapy?
5. Does the QoL change during and after therapy? (longitudinal comparison)

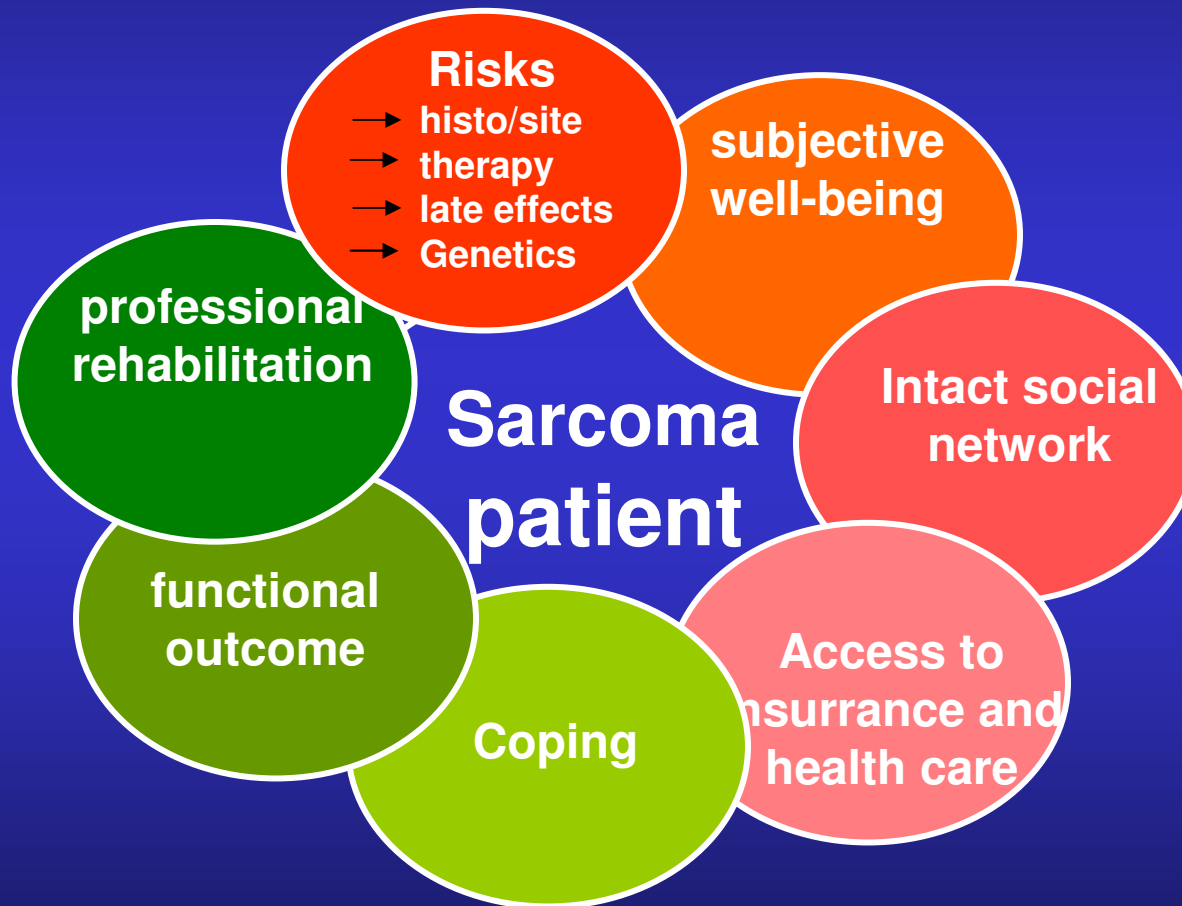
# Further areas of interest

## Influence of

- disease
- age
- treatment
- surgery
- irradiation

→ on QoL

# Quality of Survival !



# QoL working group (Münster)



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Thank you for your interest