

Parallel session 4
Hospital's management and ERN's
Irene Mathijssen
Coordinator CRANIO
November 22, 2018

ERN CRANIO

Craniofacial anomalies and ENT disorders



Multidisciplinary ERN:
Patients/parents, plastic surgery,
neurosurgery, maxfac, ENT,
ophthalmology, genetics, psychology,
speech therapy, pediatrics, ICU,
orthodontics, ...

Mainly surgery-based:
outcome requires long-term follow up
into adulthood



Patient receives questionnaire by mail



PROMS are filled out by patient at home

Data are entered in the electronic patient file

Doctors review the questionnaire before outpatient clinic



Results of the questionnaire are discussed with patient and parents

**DATA COLLECTION ALLOWS BENCHMARKING
NATIONALLY AND WITHIN ERN**

Value based health care

- Insight in organisation and quality of provided care
- Insight in wellbeing of patients, real-time
- Opens discussion on psychosocial issues, at home and in clinic
- Structured outcome over time
- “shared decision making” based on the results
- Benchmarking for best practice

Added value for:

Patients

Doctors

The hospital

Insurance companies

Ministry of Health