

Systematic review on quality of life measures in eczema trials

Current status and first results

Daniel Heinl, Joanne Chalmers & Christian Apfelbacher
Medizinische Soziologie
Institut für Epidemiologie und Präventivmedizin
Fakultät Medizin



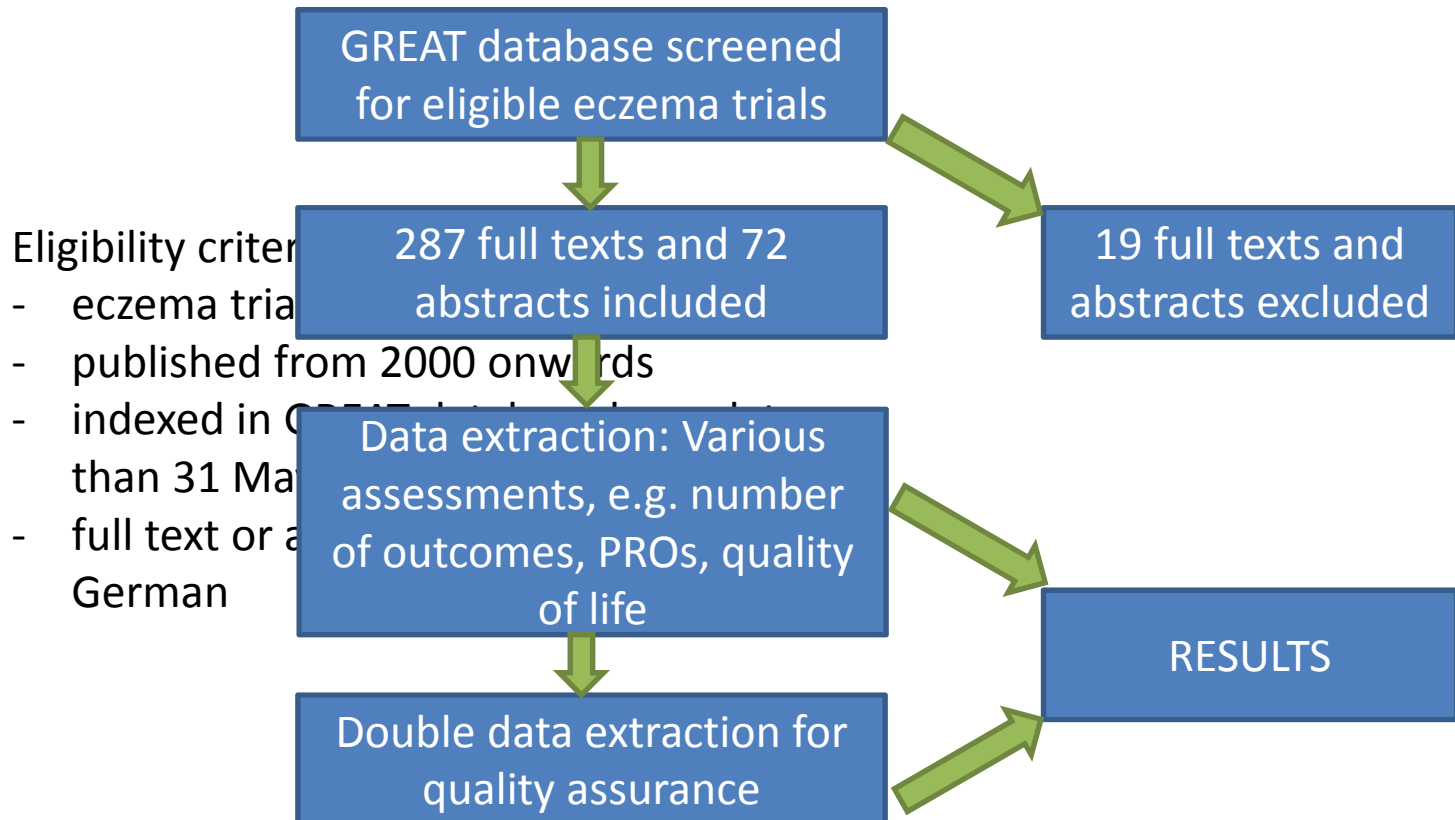
Background (1)

- Eczema is a common skin disease that affects both children and adults
- Eczema takes a chronic or chronically relapsing course, main symptom is pruritus
- Eczema exerts a negative impact on the quality of life (QoL) of patients and their families

Background (2)

- Due to unstandardized outcomes measures in eczema trials, evidence based decision making is difficult
- Therefore, the Harmonising Outcomes for Eczema (HOME) initiative defined a core set of outcome domains (COS) to be applied in all future eczema trials
- QoL is part of this COS
- A systematic review on QoL measures used in eczema trials is the first step of the HOME roadmap

Methods



Data extraction

Full texts

- Number of outcomes, total
- Number of outcomes, reported
- Number of PROs
- Number of PROs, reported
- Number of composite indices
- Number of composite indices, reported
- Number of indices used
- Number of validated indices used

Full texts (cont.)

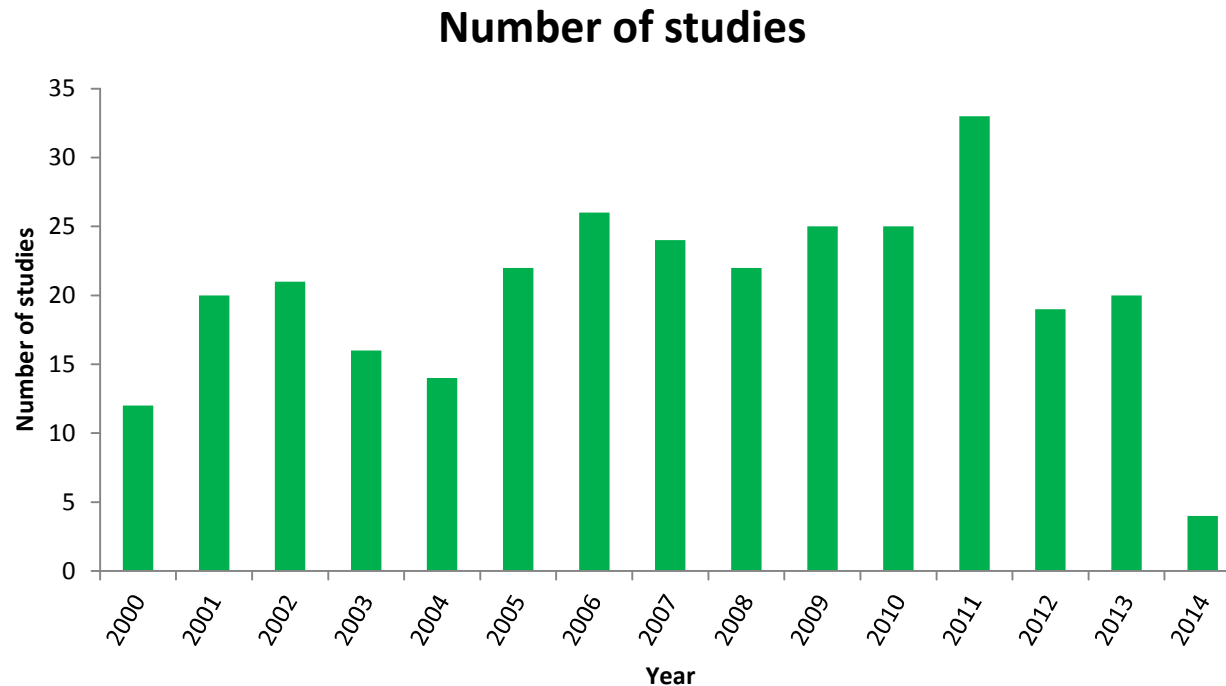
- Assessment of safety
- Assessment of adverse events
- Primary endpoint
- Assessment of QoL
- QoL instruments used

Abstracts

- Assessment of QoL
- QoL instruments used

Results – full texts

287 papers reporting on 303 studies



Results – full texts

| Outcome | Result |
|---|--------------|
| Number of outcomes, total | 2,633 |
| Percentage of PROs (including composite indices), total | 30.73% (809) |
| Percentage of composite indices, total | 6.68% (176) |
| Percentage of PROs (without composite indices), total | 24.04% (633) |
| Number of full text articles | 287 |
| Number of studies | 303 |
| Studies assessing quality of life | 20.79% (63) |
| Quality of life instruments used | 22 |

Results – quality of life (adults)

| Instrument | Number of studies | Full name (Reference) |
|-----------------|-------------------|--|
| DLQI | 20 (56%) | Dermatology Life Quality Index (Finlay 1994) |
| Skindex-29 | 2 (6%) | (Chren 1997) |
| Subtotal | 22 (61%) | |
| TOTAL | 36 (100%) | |

Results – quality of life (adults)

| Instrument | Number of studies | Full name (Reference) |
|-----------------|-------------------|---|
| EDLQ | 1 (3%) | Everyday Life Questionnaire/Alltagsleben (Bullinger 1993) |
| EQ-5D | 1 (3%) | EuroQoI-5D (Rabin 2001) |
| SF-36 | 1 (3%) | Short form 36 (McHorney 1993) |
| SIP | 1 (3%) | Sickness Impact Profile (Gilson 1975) |
| WTP | 1 (3%) | Willingness to pay (Schiffner 2003) |
| DIELH | 1 (3%) | Deutsches Instrument zur Erfassung der Lebensqualität bei Hauterkrankungen (Schäfer 2001) |
| DLQI (modified) | 1 (3%) | Dermatology Life Quality Index (Finlay 1994) |
| FLQA-d | 1 (3%) | Freiburg Life Quality Assessment d (Augustin 2000) |
| ISDL (modified) | 1 (3%) | Impact of Chronic Skin Disease on Daily Life (Evers 2005) |
| Self-provided | 1 (3%) | (Bissonette 2010) |
| Skindex-16 | 1 (3%) | (Chren 2001) |
| Skindex-17 | 1 (3%) | (Nijsten 2006) |
| EDI | 1 (3%) | Eczema Disability Index (Salek 1993) |
| QoLIAD | 1 (3%) | Quality of Life Index for Atopic Dermatitis (Whalley 2004) |
| Subtotal | 14 (39%) | |
| TOTAL | 36 (100%) | |

Results – quality of life (children, self-reported)

| Instrument | Number of studies | Full name (Reference) |
|------------------|-------------------|--|
| CDLQI | 18 (90%) | Children’s Dermatology Life Quality Index (Lewis-Jones 1995) |
| CDLQI (modified) | 2 (10%) | Children’s Dermatology Life Quality Index (Lewis-Jones 1995) |
| TOTAL | 20 (100%) | |

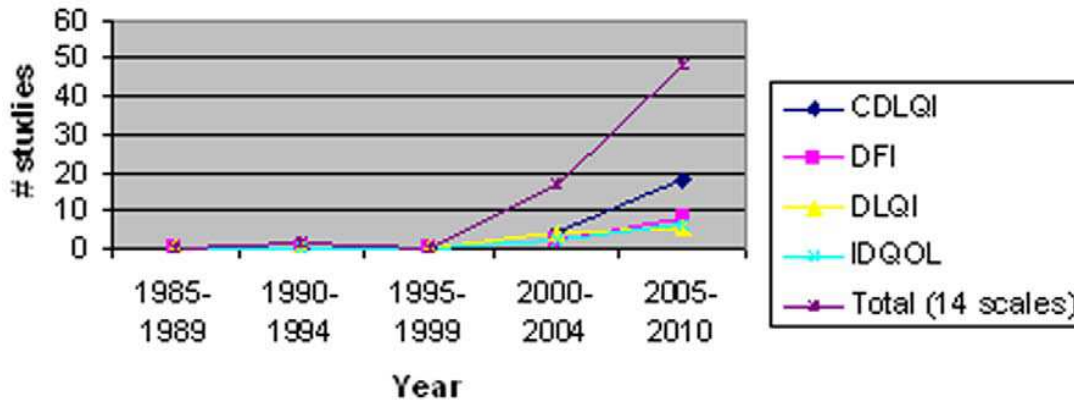
Results – quality of life (children, proxy-reported)

| Instrument | Number of studies | Full name (Reference) |
|---------------|-------------------|---|
| IDQOL | 14 (93%) | Infants' Dermatology Quality of Life Index (Lewis-Jones 2001) |
| Self-provided | 1 (7%) | (Wu 2012) |
| TOTAL | 15 (100%) | |

Results – quality of life (carers)

| Instrument | Number of studies | Full name (Reference) |
|----------------------------------|-------------------|---|
| DFI | 14 (70%) | Dermatitis Family Impact (Lawson 1998) |
| Questionnaire by Rüden et al. | 3 (15%) | (Rüden 1999) |
| PIQoL-AD | 2 (10%) | Parents' Index of Quality of Life in Atopic Dermatitis (McKenna 2005) |
| Self-provided | 1 (5%) | (Harper 2000) |
| TOTAL | 20 (100%) | |

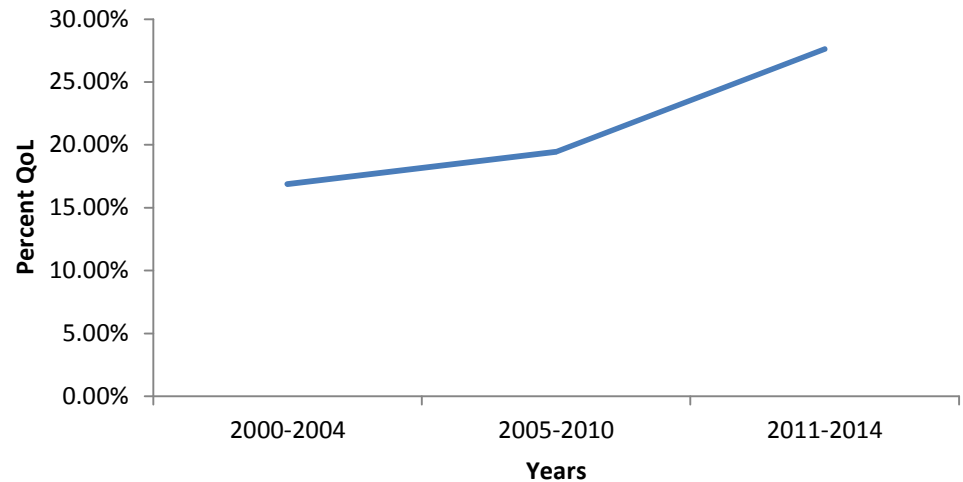
Results – quality of life over time (1)



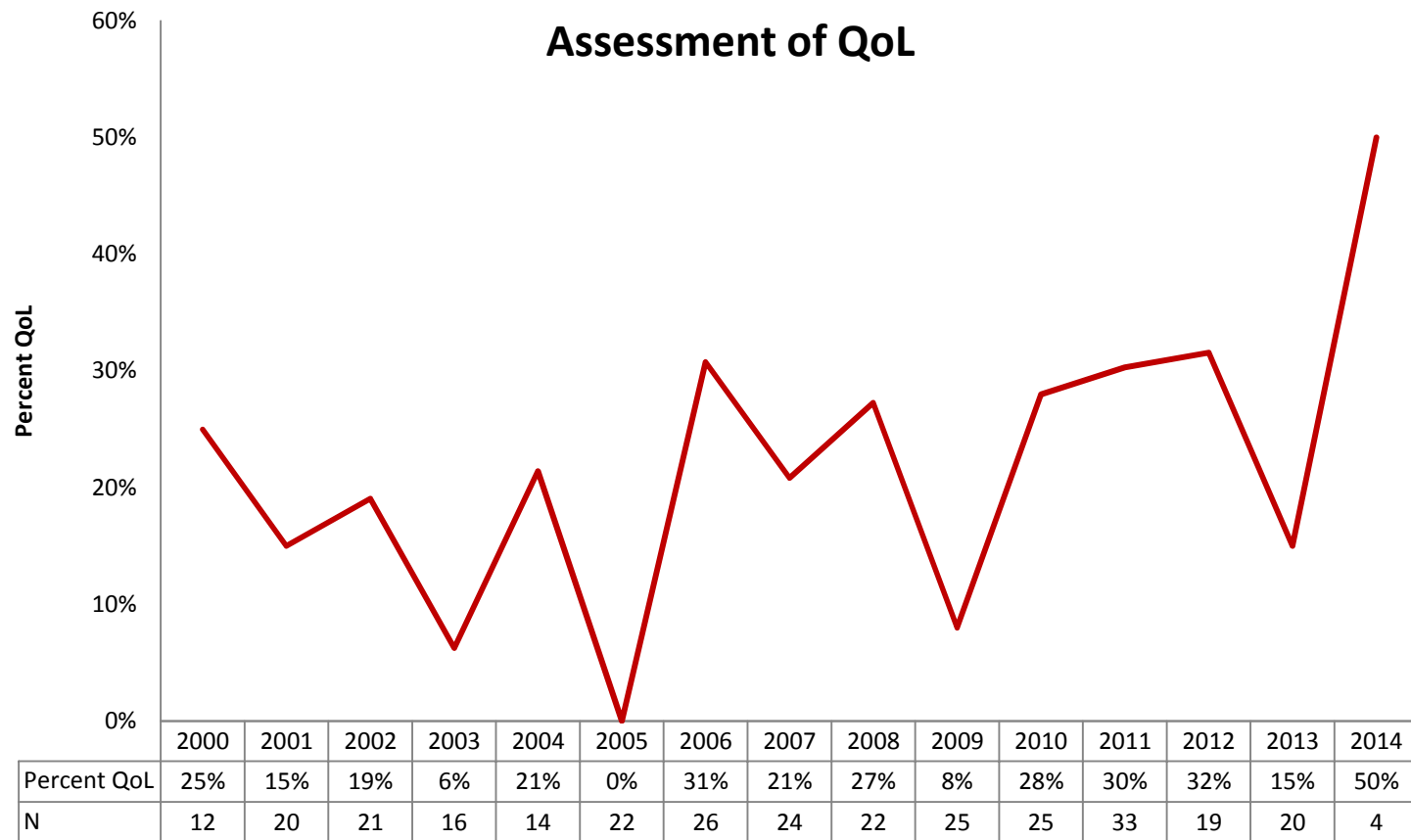
Left: Findings from Rehal 2011

Right: Our findings

Assessment of QoL



Results – quality of life over time (2)



Results - abstracts

72 abstracts included

4 abstract assessed quality of life (6%)

Applied instruments:

- **CDLQI (2x)**
- **DFI (1x)**
- **No closer specification (3x)**

Discussion

- 1 out of 5 eczema trials assesses QoL
- Measurement of QoL has not increased substantially since 2000
- Eczema-specific questionnaires are almost not used (adults, carers) or do not exist (children)



Universität Regensburg

Christian Apfelbacher
Medizinische Soziologie
Fakultät Medizin

Thank you very much for your attention!