



# HOW TO MEASURE & IMPROVE QUALITY OF LIFE IN CUTANEOUS T-CELL LYMPHOMA

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# Content

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- How's Health Related Quality of Life (HRQoL) impaired in CTCL ?
- How do we measure HRQoL in CTCL?
- How we may improve HRQoL in CTCL?
  
- How should we currently best improve HRQoL?
  - a) Better treatments
  - b) Improved symptom control
  - c) More psychological support
  - d) Increased patient information



## Why is quality of life Reduced in cutaneous T-cell lymphoma?

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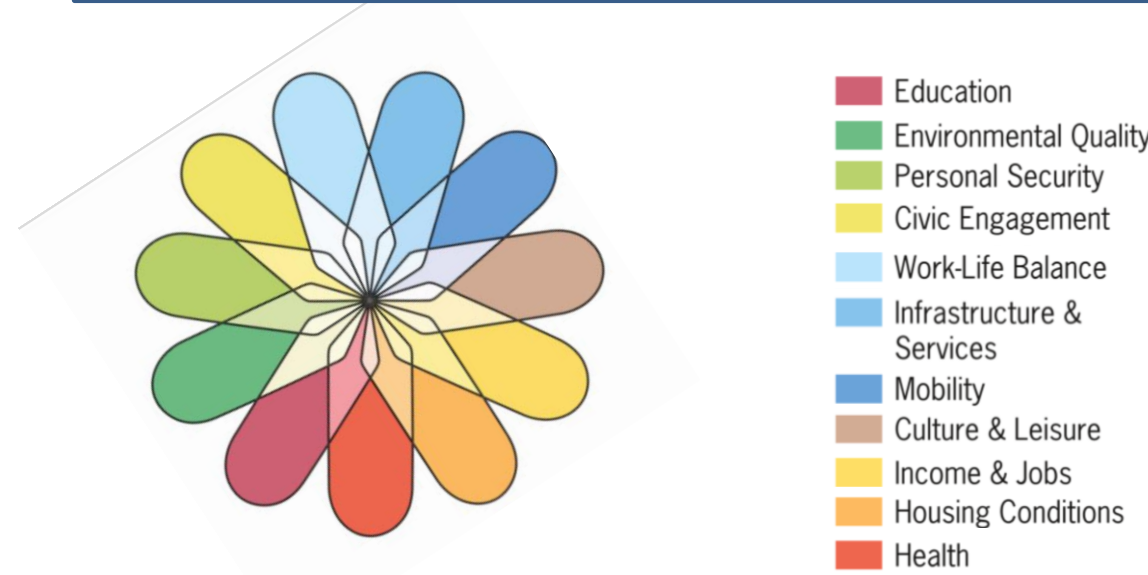
- CTCL is a visual disease
- Associated with disabling symptoms such as intractable itching (pruritus), pain, burning of skin
- CTCL is also a malignant disease of the skin with the worry of a cancer diagnosis
- Specific factors such as large or malodorous tumours, hearing loss, tiredness (malaise) and temperature dysregulation (hot/cold/shivering) may occur which are not typical of other skin diseases and may impede patients well being



# Measuring QoL/HRQoL

## QoL Definition

A state of complete physical, mental, and social well-being not merely the absence of disease



## HRQoL Definition

Health related quality of life (HRQoL) is a subset relating only to the health domain of that existence



# HRQoL: Terminology

- Health related QoL (HRQoL) –focuses on the **effects of illness and specifically treatment** on QoL

## European Organisation or Research & Treatment of Cancer

**(EORTC) definition of HRQoL** - the subjective perceptions of both the positive & negative aspects of cancer patients' symptoms, including physical, emotional, social & cognitive functions &, importantly, disease symptoms & side effects of treatment

- **Issues** are symptoms such as itching/pain can be measured by selecting '**items**' which are questions that encompass the **issues**
- **Measures** are the HRQoL questionnaires developed to test a persons' health state by asking **items** on the relevant **issues** for their disease



# CTCL HRQoL Issues



Painful hands

Pain



Disfiguring



Weeping, painful visual lesions



Visual loss/hearing loss



Fungating  
malodorous tumours

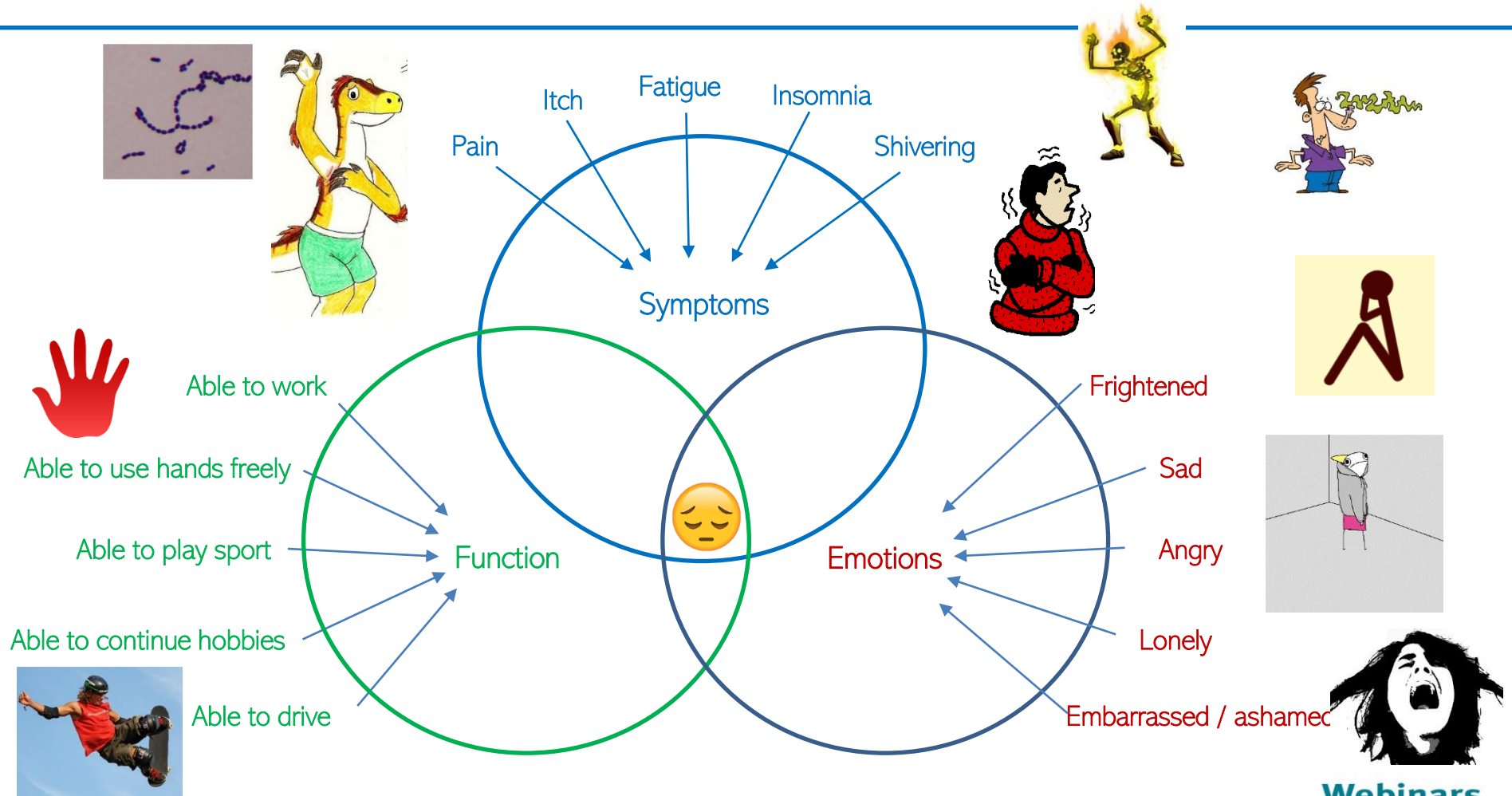


Itching





# CTCL issues affecting HRQoL

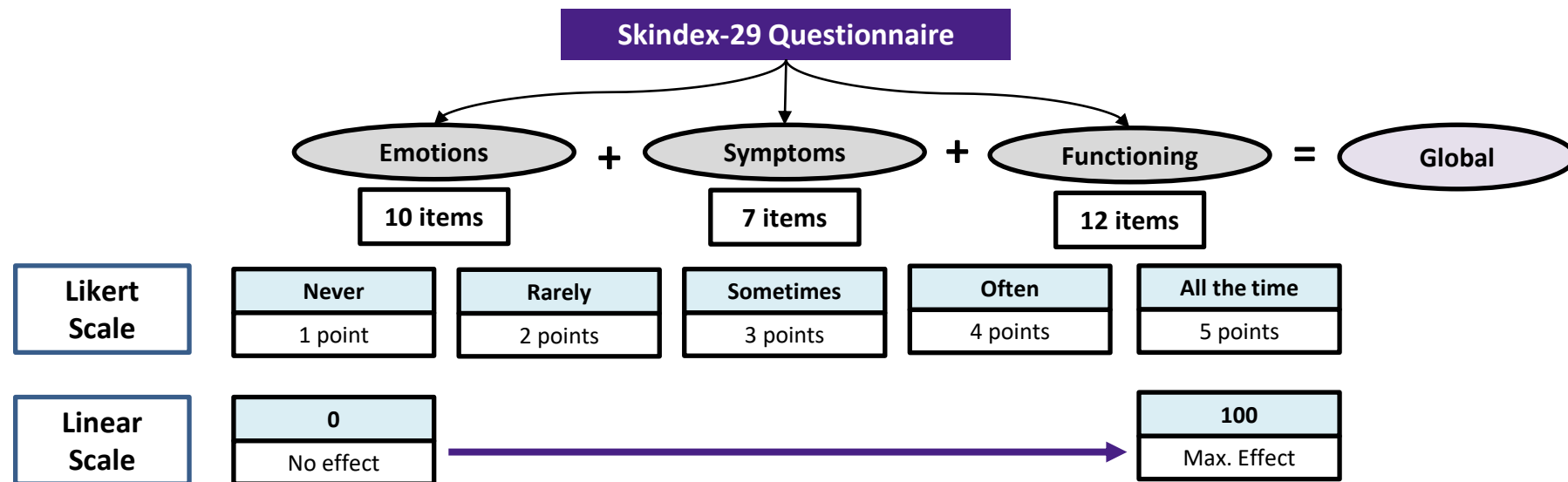




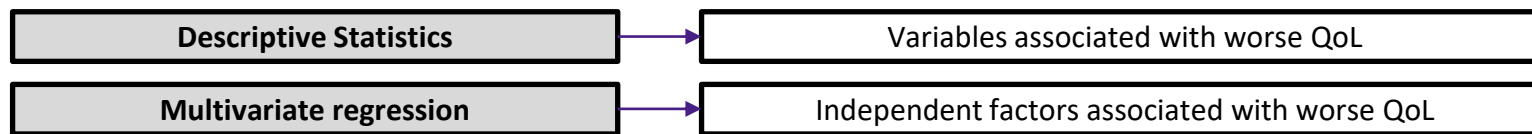
# How we Measure Quality of Life in CTCL; Current situation

- We combine several QOL questionnaires to cover most aspects of cutaneous lymphoma (average of 3-4 per study)
- A variety of questionnaires are used & include;
  - The Functional Assessment of Cancer Therapy– General (FACT-G)
  - EORTC QLQ-C30 questionnaires
  - EQ-5D-3L (from Euro QOL gp)
  - Skindex 29
  - 12 item MF/SS CTCL questionnaire patientslikeme®
  - Illness Perception Questionnaire (IPQ-R)
  - Pruritus Visual Analog Scale, Pruritus scale, VASitch, Pruritus related Life Quality Index (PLQI), Likert scale & Itchy QoL
- This is time consuming for the patient and combining different questionnaires makes results to interpret and compare between studies as there is no standard combination





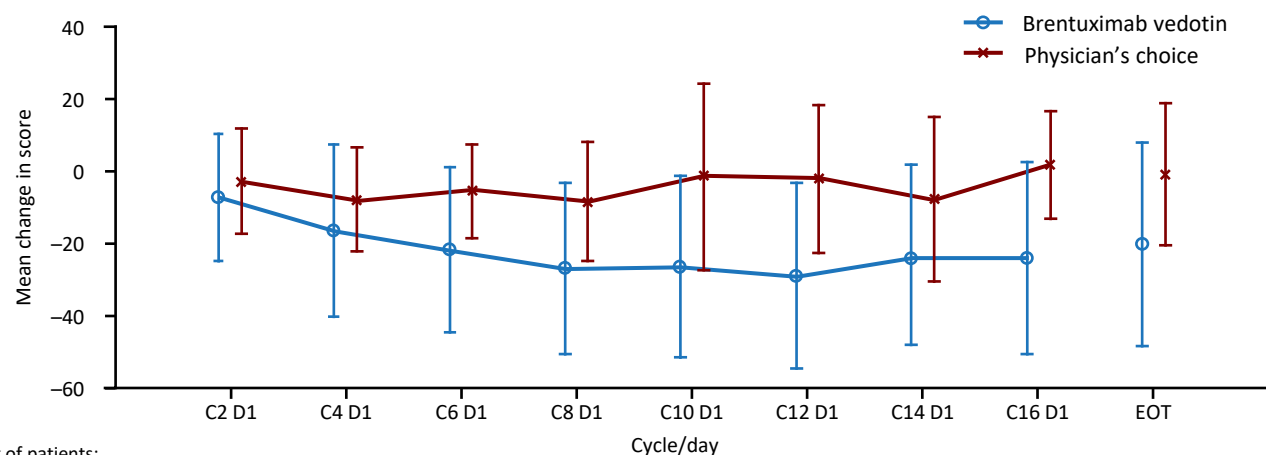
**Data Analysis**





## Alcanza Study - QoL per changes in symptom domain by Skindex-29 questionnaire

- Patient-reported QoL assessed by Skindex-29 questionnaire showed significantly greater symptom reduction for patients receiving brentuximab vedotin versus physician's choice (mean maximum reduction  $-28.08$  vs  $-8.62$ ;  $p < 0.001$ )

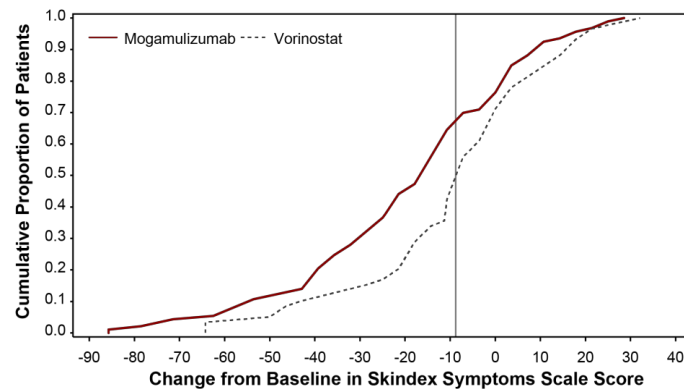


	C2 D1	C4 D1	C6 D1	C8 D1	C10 D1	C12 D1	C14 D1	C16 D1	EOT
Number of patients:									
Brentuximab vedotin	56	50	40	37	36	25	25	22	47
Physician's choice	45	30	25	14	13	8	5	3	37



# Mavoric Study: Patient-reported symptom reduction as measured by the Skindex-29 scale

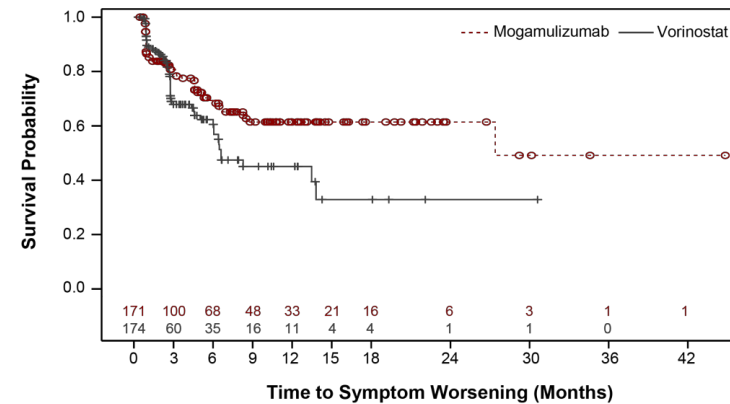
CDF Curve of Skindex-29 Symptoms Scale Score at Cycle 5



CDF, cumulative distribution function

- The Skindex-29 Symptoms Scale scores demonstrated statistically significant improvements in favor of the mogamulizumab-treated patients vs the vorinostat-treated patients at Cycles 3, 5, and 7 ( $P < 0.05$ )




Time to Symptom Worsening of Skindex-29 Symptoms Scale Score



- Median time to meaningful deterioration on the Skindex-29 Symptoms Scale was 27 months for mogamulizumab versus 7 months for vorinostat



## Characteristics associated with significantly worse quality of life in mycosis fungoides/Sézary syndrome from the Prospective Cutaneous Lymphoma International Prognostic Index (PROCLIP) study

K. Molloy <sup>1</sup> C. Jonak,<sup>2</sup> F.J.S.H. Woei-A-Jin,<sup>3</sup> E. Guenova,<sup>4</sup> A.M. Busschots,<sup>3</sup> A. Bervoets,<sup>3</sup> E. Hauben,<sup>3</sup> R. Knobler,<sup>2</sup> S. Porkert,<sup>2</sup> C. Fassnacht,<sup>4</sup> R. Cowan,<sup>5</sup> E. Papadavid,<sup>6</sup> M. Beylot-Barry <sup>7</sup> E. Berti,<sup>8</sup> S. Alberti Violetti,<sup>8</sup> T. Estrach,<sup>9</sup> R. Matin,<sup>10</sup> O. Akilov <sup>11</sup> L. Vakeva,<sup>12</sup> M. Prince,<sup>13</sup> A. Bates,<sup>14</sup> M. Bayne,<sup>15</sup> R. Wachsmuch,<sup>16</sup> U. Wehkamp,<sup>17</sup> M. Marschalko,<sup>18</sup> O. Servitje,<sup>19</sup> D. Turner,<sup>20</sup> S. Weatherhead,<sup>21</sup> M. Wobser,<sup>22</sup> J.A. Sanches,<sup>23</sup> P. McKay,<sup>24</sup> D. Klemke,<sup>25</sup> C. Peng,<sup>1</sup> A. Howles,<sup>1</sup> J. Yoo,<sup>1</sup> F. Evison<sup>1</sup> and J. Scarisbrick<sup>1</sup>

<sup>1</sup>University Hospitals Birmingham, Birmingham, U.K.

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# To identify factors associated with poorer health-related quality of life (HRQoL) in patients newly diagnosed with MF/SS

## Methods:

- Patients enrolled into Prospective Cutaneous Lymphoma International Prognostic Index (PROCLIPi) had their HRQoL assessed using the Skindex-29 questionnaire & scores were analysed in relation to patient- and disease-specific characteristics.

## Results:

The study population consisted of 237 patients [3:2 male:female; median age 60 years, 179 early MF and 58 d advanced MF/SS

- In univariate analysis HRQoL was worse,
  1. Female gender
  2. Alopecia
  3. Sezary syndrome
  4. Late-stage MF
  5. Elevated blood serum LDH
  6. High skin mSWAT count
  7. Confluent erythema
- In multivariate analysis only female gender ( $p=0.003$ ) and alopecia ( $p=0.02$ ) were independent predictors of worse global HRQoL



# PROCLIFI: HRQoL Update

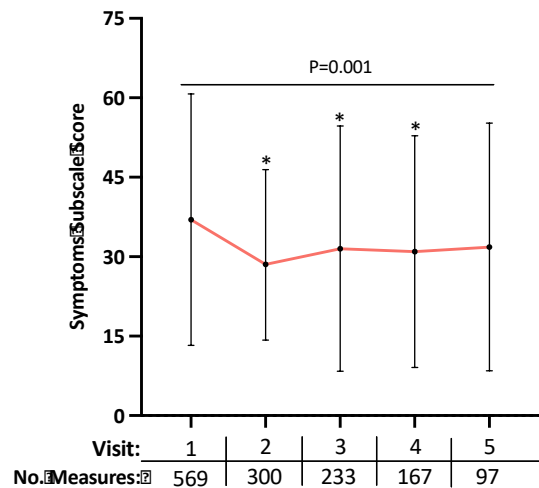
Total Number of Skindex-29 measures	1595								
No. Individuals	814								
Age (Median, IQR)	60 (47 – 70) years								
Sex	Males (519); Female (295) - Ratio 1.75								
EORTC Classification	<table><tr><td>Classical MF</td><td>614 (75.4%)</td></tr><tr><td>Folliculotropic MF</td><td>108 (13.3%)</td></tr><tr><td>Sezary Syndrome</td><td>88 (10.8%)</td></tr><tr><td>Pagetoid Reticulosis</td><td>6 (0.7%)</td></tr></table>	Classical MF	614 (75.4%)	Folliculotropic MF	108 (13.3%)	Sezary Syndrome	88 (10.8%)	Pagetoid Reticulosis	6 (0.7%)
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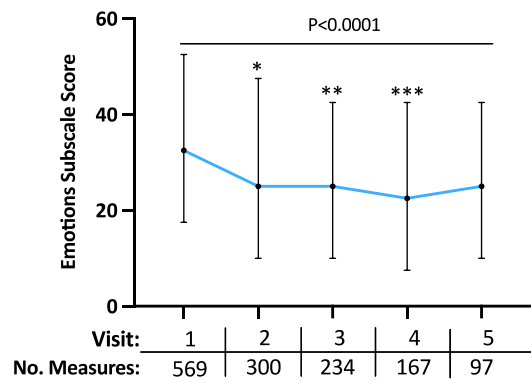


# PROCLIFI: HRQoL Update

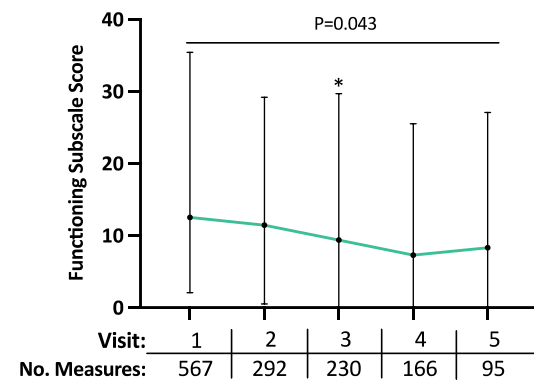
## Change in Skindex-29 Scores Over Time



Symptoms



Emotions



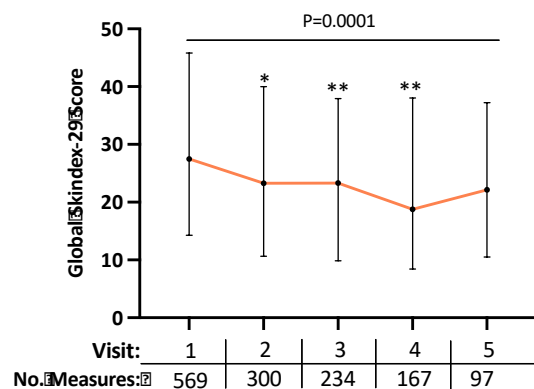
Functioning



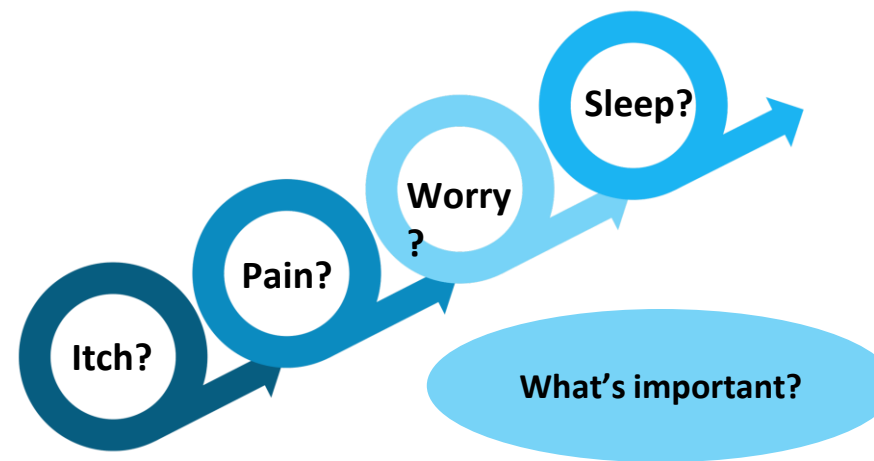
# PROCLIFI: HRQoL Update

## Change in Skindex-29 Scores Over Time

HRQoL improves from Visit 1 to Visit 2



Global





# PROCLIFI: HRQoL Update

## What are the individual responses telling us?

HOW OFTEN DURING THE PAST FOUR WEEKS DO THESE STATEMENTS DESCRIBE YOU?

NEVER   RARELY   SOMETIMES   **OFTEN**   ALL THE TIME

1. My skin hurts . . . . . 1   2   3   4   5

Which items on the Skindex-29 questionnaire are respondents rating at "Often" or "All the Time"?



# PROCLIFI: HRQoL Update



## Ranking of the Top 15 Items Scored "Often" or "All the time"

### Learning Points

Emotional items are ranked as the top 2

Skin symptoms are important: *itching, sensitivity, irritated*

Emotions:  
*Annoyance, Frustration, Anger, embarrassment*



# PROPOSAL

## DEVELOP A SKIN LYMPHOMA SPECIFIC QOL QUESTIONNAIRE JOINT EORTC CLTF & EORTC QOL GROUP

**Leads:** Simone Oerlemans, Julia Scarisbrick,

**Co-Investigators:** Constanze Jonak, Antonio Cozzio, Ulrike Wehkemp & Pietro Quaglino

**Grant awarded by EORTC 2019**



## EORTC/CTLF QOL Questionnaire specific for Cutaneous Lymphoma

For all skin lymphoma, cover low grade B-cell, early stage MF, advanced MF/SS and aggressive B-cell

- CTCL other than MF and CBCL may only have more minor HRQoL issues and must be Qs to reflect all stages

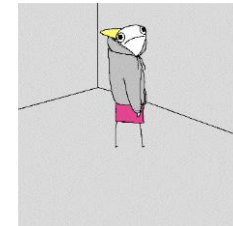
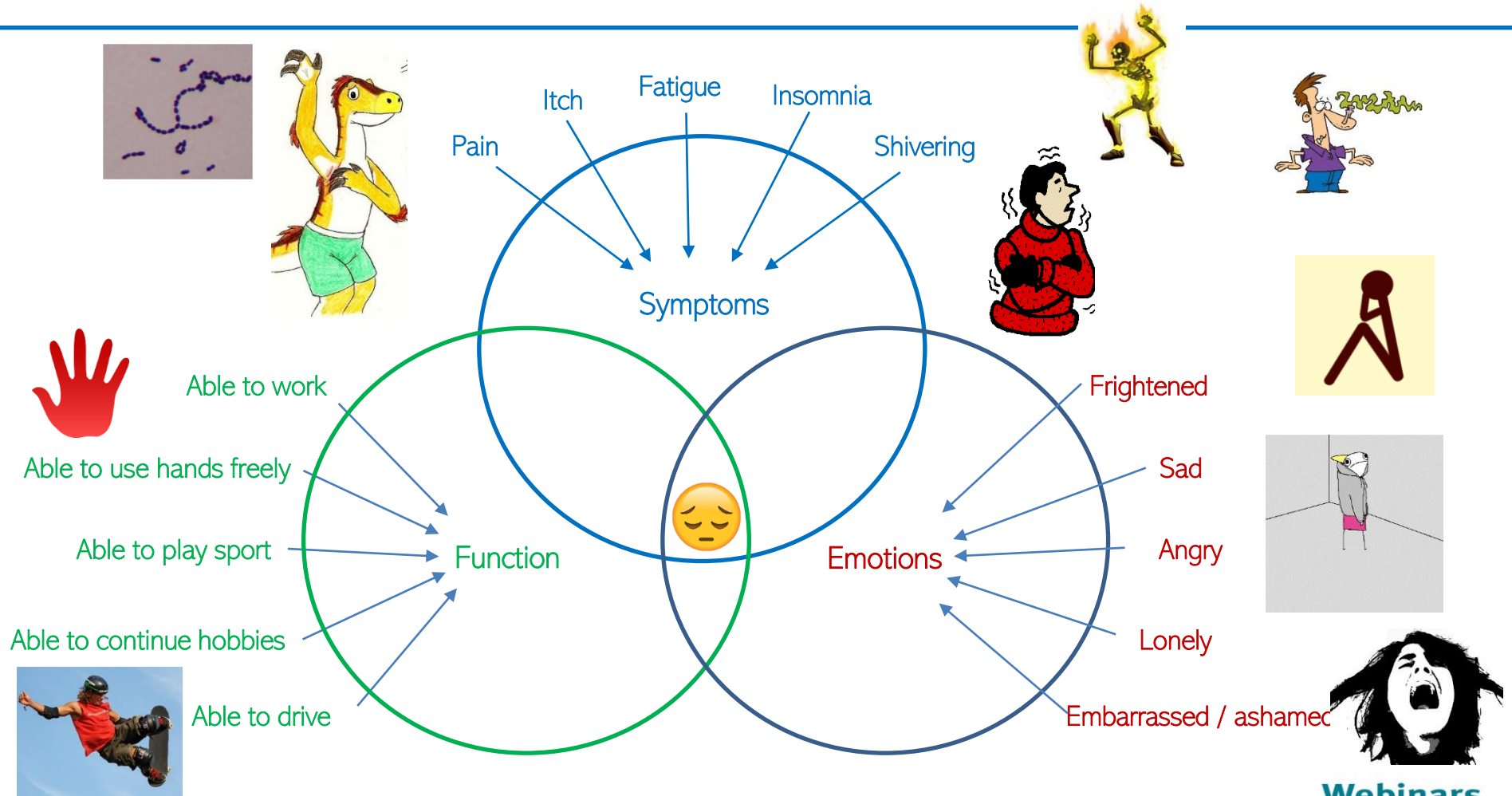
Questionnaire has to (be):

- ✓ Not time consuming
- ✓ Easy to understand and to complete
- ✓ Specific for the disease
- ✓ Consider age and gender differences
- ✓ Validated
- ✓ Translation into national languages





# How can we currently improve HRQoL?





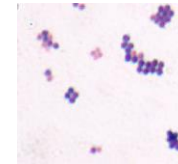
# Supportive Care to improve HRQoL

A holistic approach to treatment aiming to improve HRQoL should include symptom, emotional and functional support

- Pruritus treatment for itching
  - Moisturisers
  - Antihistamines, doxepin
  - Gabapentin
  - Aprepitant, Mirtazapine
  - Naltrexone
- Skin infections treatment
  - Anti-bacterial agents
  - Anti-viral agents
  - Bleach baths
- Pain relief
  - Paracetamol / Codeine
  - Morphine
- Insomnia help with sleeping
  - Counselling
  - Sleeping tablets
- Functional support
  - Dressings
  - Pain Relief
  - Physiotherapy
- Psychological support
  - Cancer psychologist
  - Patient help groups
  - Antidepressants



Depression



Skin infections – Staph aureus



Pruritus



Social isolation



Loss of body heat, shivering

Living with a cancer diagnosis



Pain



Painful hands



# JENNI TALK

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**European  
Reference  
Network**

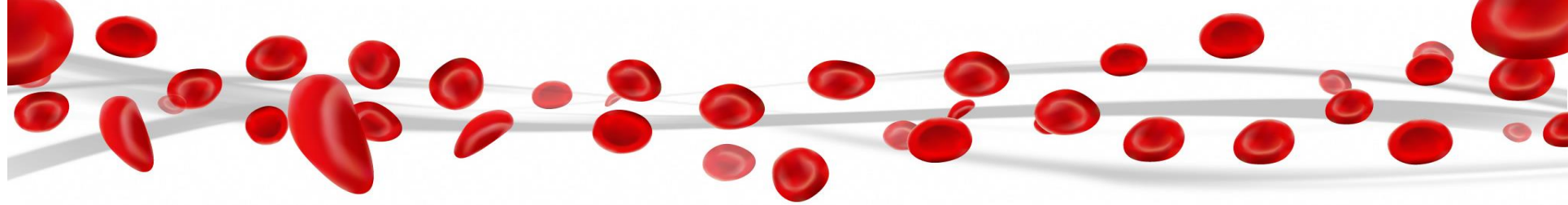
for rare or low prevalence  
complex diseases

Network  
Hematological  
Diseases (ERN EuroBloodNet)

Webinars  
**Cutaneous Lymphoma**

EuroBloodNet  Topic on Focus

Patients' Organizations



## Discussion



## Questions

Correct answer question

Health Related Quality of life (HRQOL)in CTCL is entirely related to symptom burden

True / False

Answer – false also includes emotions and functions

Opinion questions

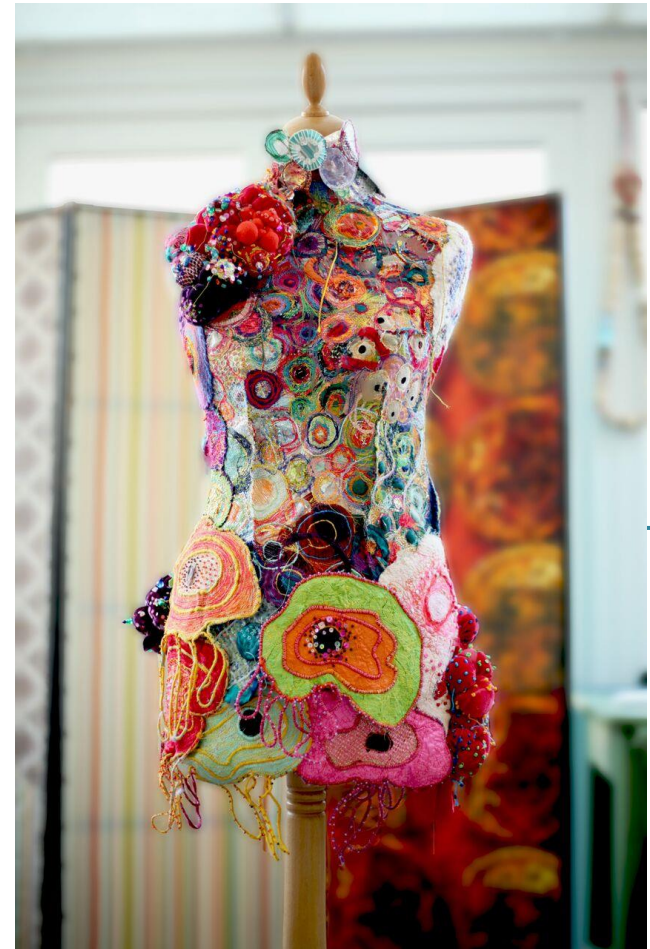
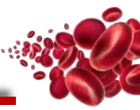
Which of the following do you believe to be more important factor in improving HRQOL in CTCL patients in the future ?

- a) Improving survival
- b) Better treatment responses
- c) Improved symptom relief

How should we currently best improve HRQOL?

- a) Offer psychological support
- b) Improve patient information
- c) Offer more symptomatic treatment alongside anti CTCL therapy





European  
Reference  
Network

for rare or low prevalence  
complex diseases

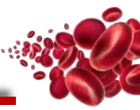
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## Webinars Cutaneous Lymphoma

EuroBloodNet  Topic on Focus

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