

Capturing the Patient Journey using Electronic Patient Reported Outcome Measures (ePROMs) in Cutaneous Lymphomas



Nicholas Lawrance, Nina
Farquharson, Eileen Parry,
Christina Hague, Richard Cowan
The Christie NHS Foundation Trust, University
of Manchester

WCCL April 12th 2024



Disclosures

- Kyowa Kirin Medical Advisor



ePROMs in Cutaneous Lymphoma

- Electronic system with the ability to capture the impact on QoL for our patients with Cutaneous Lymphoma
- Patients are invited to complete questionnaires in their home surroundings in their own time (in discussion with their carers)
- The responses are available for the clinician to review prior to seeing the patient in the clinic
- The patient responses are permanently captured in the electronic patient record

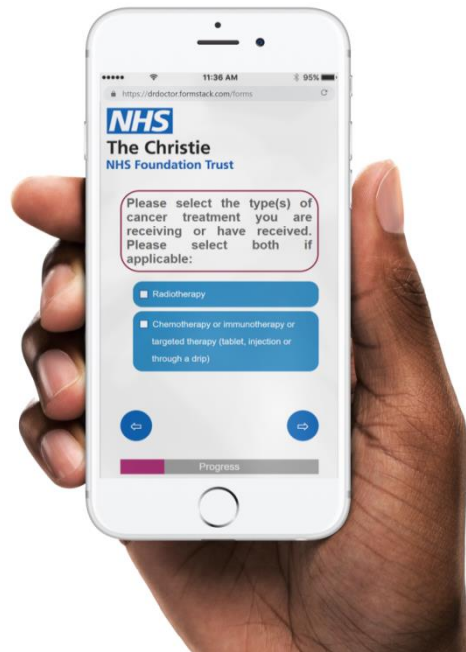


ePROMs in Cutaneous Lymphoma

- The ePROMS questionnaire comprises :
 - Skindex-16. 3 domains :
 - symptoms, emotion and function
 - EuroQol EQ-5D-5L
- Section for free text : “Is there anything else you would like your consultant to know?”
- Sent via text message 5 days prior to clinic appointment



Patient experience- Questionnaire



Patient view

The below set of questions ask about your symptoms from your skin.

Please select the number most applicable to you on a scale of 0 - 6. Where:

0 means **Never Bothered** and 6 means **Always Bothered**

- | | |
|---|---|
| Your skin condition itching | 2 |
| Your skin condition burning or stinging | 2 |
| Your skin condition hurting | 2 |
| Your skin condition being irritated | 3 |
| The persistence/reoccurrence of your skin condition | 5 |



ePROMS feasibility and evaluation

- 2021 feasibility study
 - 76% response rate
- Structured interviews to assess patient and clinician perspective:
 - 19 patients
 - 3 clinicians interviewed
- Patients :
 - Positive responses
 - Barriers : included lack of smartphone or internet access
- Clinicians
 - Extra time in reviewing the ePROMs prior to seeing the patient (improved with familiarity)

Crooks GJ, et al. *European Journal of Cancer*. 2021;156:S66-S67.



THESE QUESTIONS CONCERN THE SKIN CONDITION WHICH HAS BOTHERED YOU THE MOST DURING THE PAST 7 DAYS

During the past 7 days, how often have you been bothered by:

Never Bothered
↓

Always Bothered
↓

	0	1	2	3	4	5	6
1. Your skin condition itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Your skin condition burning or stinging	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Your skin condition hurting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Your skin condition being irritated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. The persistence / reoccurrence of your skin condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Worry about your skin condition <u>(For example: that it will spread, get worse, scar, be unpredictable, etc)</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. The appearance of your skin condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Frustration about your skin condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Embarrassment about your skin condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Being annoyed about your skin condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Feeling depressed about your skin condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. The effects of your skin condition on your interactions with others <u>(For example: interactions with family, friends, close relationships, etc)</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. The effects of your skin condition on your desire to be with people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Your skin condition making it hard to show affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. The effects of your skin condition on your daily activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Your skin condition making it hard to work or do what you enjoy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Have you answered every item? Yes No

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN / DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY / DEPRESSION

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

ePROMs in Cutaneous Lymphoma

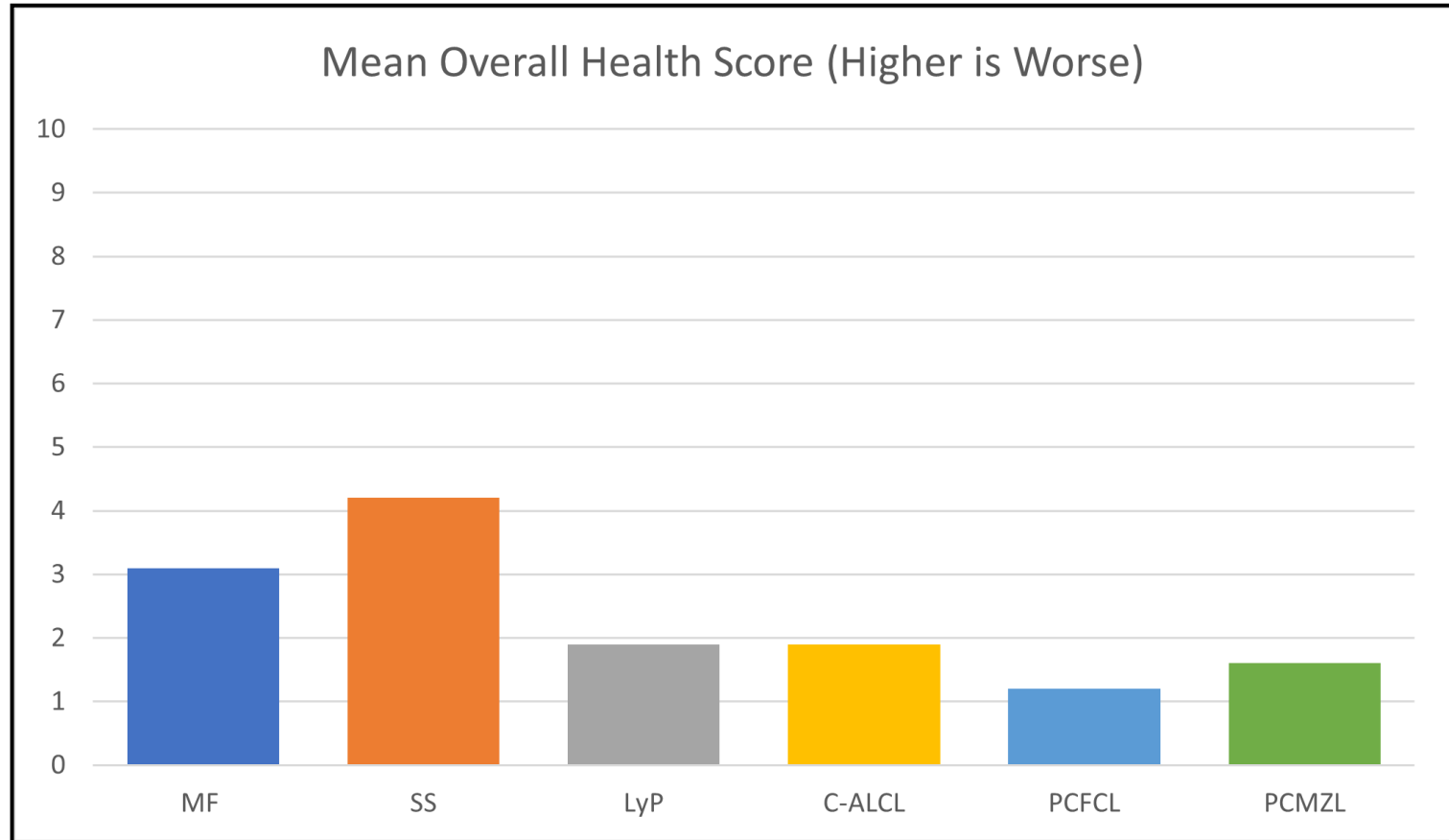
Dec 2020 – September 2023

208 patients

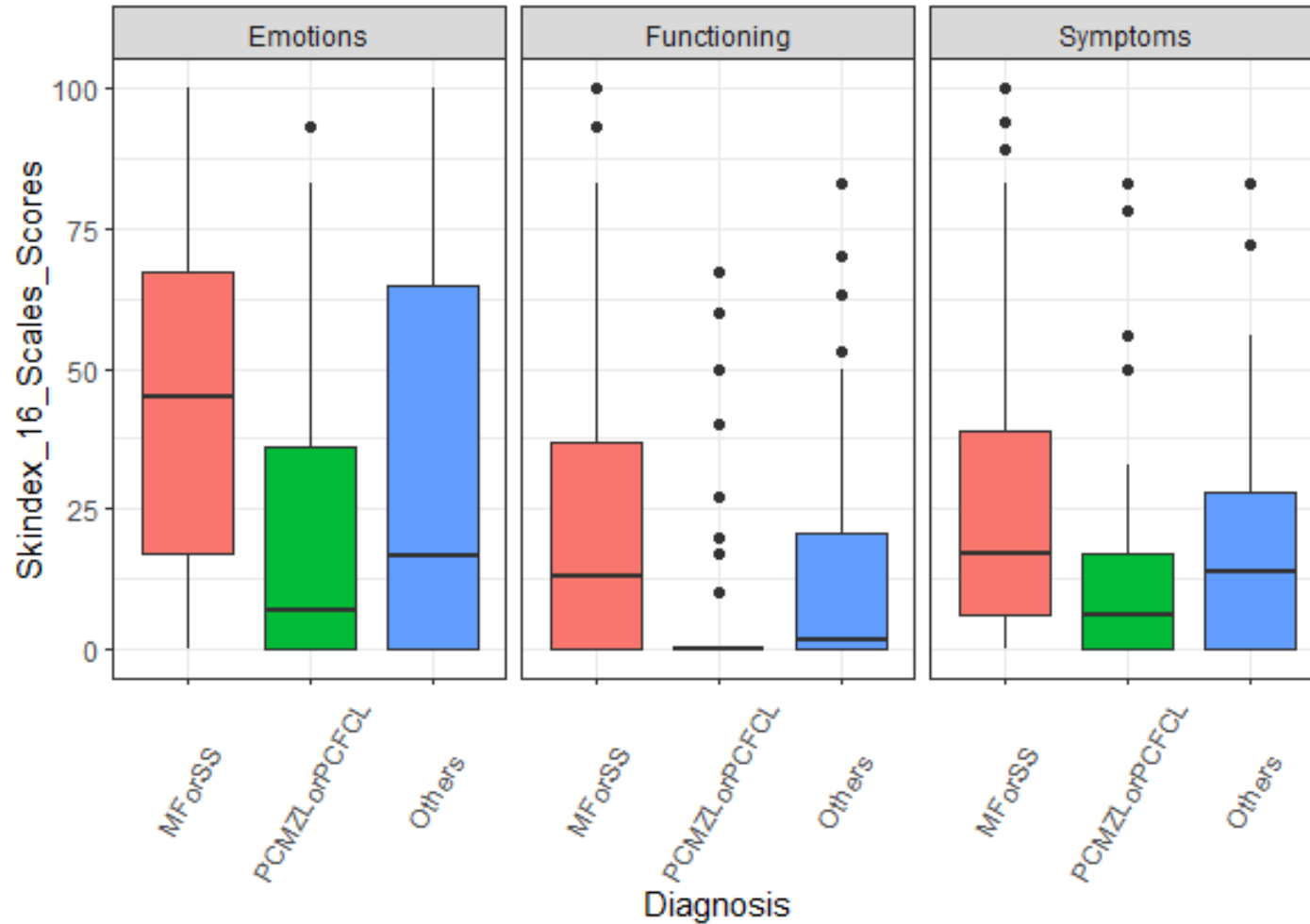
- 69% Male
- Age 65 (28 – 95)
- MF = 107
- SS = 15
- B Cell 46
- Others 40
- 153 completed more than one form (2 – 16)
- 36 patients filled in the questionnaire 5 or more times
- 70% of MF early stage



Mean overall health score for all patients



Skindex-16 – Diagnosis Category

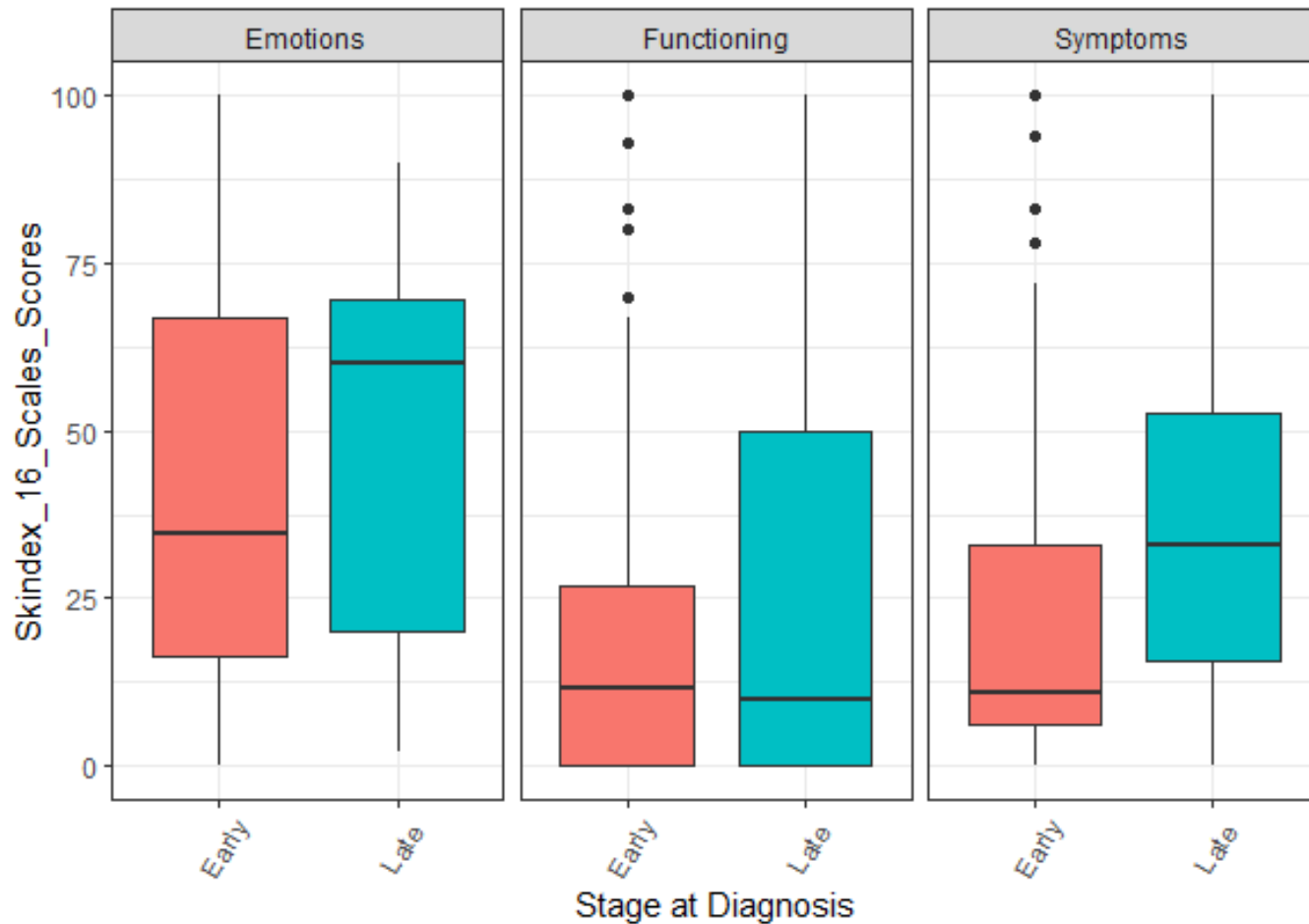


Skindex 16

Skindex_16	Diagnosis Category	Min	1st Quartile	Median	Mean	3rd Quartile	Max	Kruskal-Wallis Test P value
Emotions	MF or SS	0	17	45	44.17	67	100	<0.0001
	PCMZL or PCFCL	0	0	7	19.80	36.25	93	
	Others	0	0	16.5	33.15	64.75	100	
Functioning	MF or SS	0	0	13	22.42	37	100	<0.0001
	PCMZL or PCFCL	0	0	0	6.70	0	67	
	Others	0	0	1.5	14.05	20.75	83	
Symptoms	MF or SS	0	6	17	25.80	39	100	0.0105
	PCMZL or PCFCL	0	0	6	14.72	17	83	
	Others	0	0	14	18.05	28	83	



Skindex-16 – Early/Late Stage



ePROMs Scoring

Skindex- 16- Higher scores
are worse

EQ5D Lower scores are worse

For analysis:

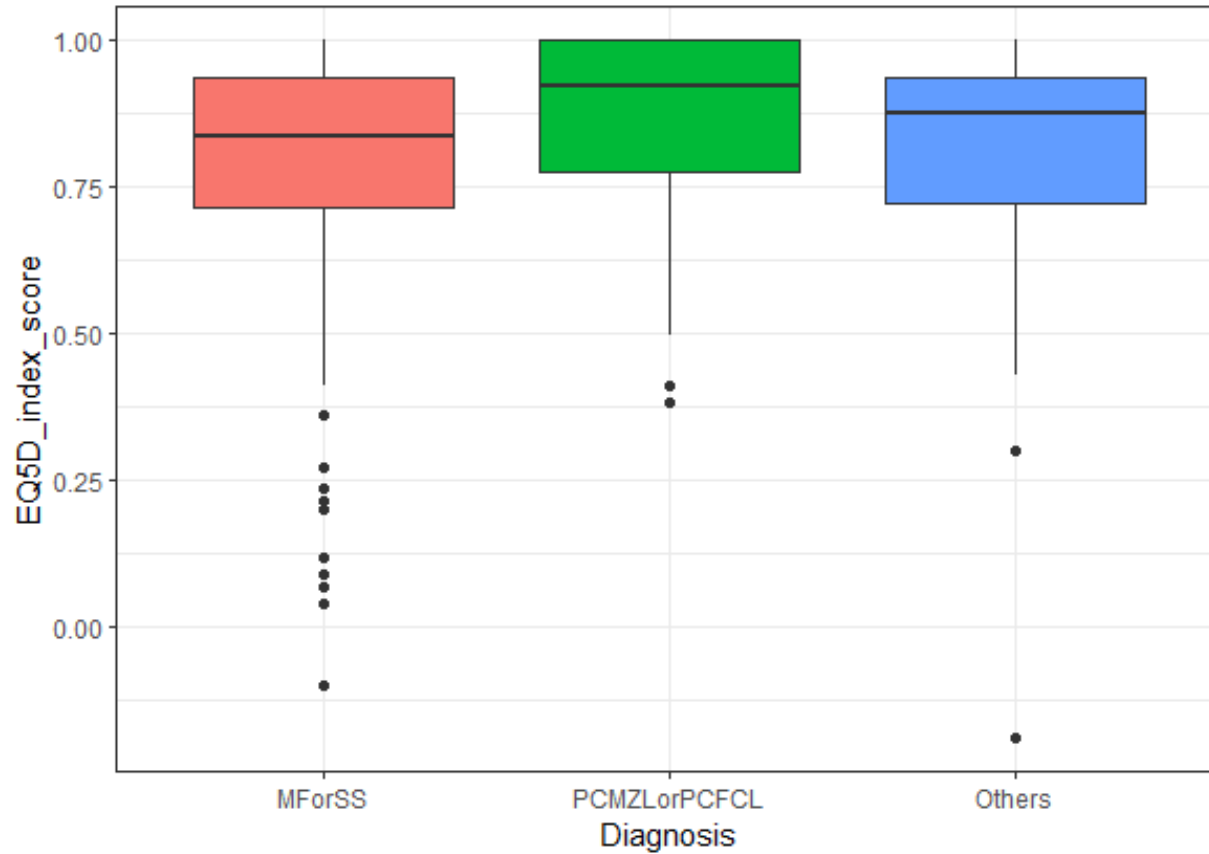
Mild: Score 0, 1 or 2

Severe: Score 3, 4, 5, 6



		Skindex-16 Items	MF or SS (122)			
			Mild		Severe	
Symptoms	1	Your_skin_condition_itching	71	58.2%	51	41.8%
	2	Your_skin_condition_burning_or_stinging	94	77.0%	28	23.0%
	3	Your_skin_condition_hurting	101	82.8%	21	17.2%
Emotions	5	The_persistence__reoccurrence_of_your_skin_condition	47	38.5%	75	61.5%
	6	Worry_about_your_skin_condition	53	43.4%	69	56.6%
	7	The_appearance_of_your_skin_condition	51	41.8%	71	58.2%
	8	Frustration_about_your_skin_condition	54	44.3%	68	55.7%
	9	Embarrassment_about_your_skin_condition	70	57.4%	52	42.6%
	10	Being_annoyed_about_your_skin_condition	66	54.1%	56	45.9%
	11	Feeling_depressed_about_your_skin_condition	71	58.2%	51	41.8%
Functioning	12	The_effects_of_your_skin_condition_on_your_interactions_with_others	95	77.9%	27	22.1%
	13	The_effects_of_your_skin_condition_on_your_desire__to_be_with_people	95	77.9%	27	22.1%
	14	Your_skin_condition_making_it_hard_to_show_affection	98	80.3%	24	19.7%
	15	The_effects_of_your_skin_condition_on_your_daily_activities	87	71.3%	35	28.7%
	16	Your_skin_condition_making_it_hard_to_work_or_do_what_you_enjoy	83	68.0%	39	32.0%

EQ5D questionnaire



Practical Limitations

- Patient requires access to appropriate technology
- May increase time spent reviewing responses prior to seeing patients



Results summary

- Over 40% patients with MF and SS suffer distressing itch
- 42 % - 62% patients with MF and SS report significant psychological symptoms
- The SS patient cohort experience a greater symptomatic and psychological impact than MF



Results summary

- Indolent cutaneous B cell lymphomas report significantly better quality of life than MF/SS
- Late stage disease have worse quality of life scores than early stage disease
- No significant difference by gender or age



Future potential of ePROMs

- Embedded in the routine assessment and management of patients automatically recording the responses in the patient record
- Dynamic assessment of impact of disease on the patient
 - Analysis of change over time
 - Response to treatment
 - Comparisons in clinical trials
- Allows remote virtual assessment
 - Determining the frequency and format follow up
 - Tailor support for patients between out patient visits



Thank you



Dr Christina Hague, Dr Nina Farquarson, Dr Nick Lawrance



Our initial data does not show significant difference in skindex 16 by gender or age

