

**Methotrexate and Prednisolone study in Erythema Nodosum Leprosum** MaPs in ENL Training session 10 – **Participant Reported** Outcome measurement and Quality of life questionnaires Dr. Barbara de Barros – MaPs study manager





The Leprosy Mission Trust India





ENLIST





### Patient reported outcome measure

- Patient reported outcome measure
- Health-related Quality of Life questionnaires HRQoL
  - Dermatology Life Quality Index (DLQI)
  - 36-Item Short Form Survey (SF-36)

# Participant reported Outcome measure - PROM

- Participant centered research
- Objectively captures participant perception of health
- Standardised outcome

### What is a HRQoL questionnaire?

- Tool to assess how participants perceive health
- Validated tool
- Objective outcome
- Dermatology Quality of Life Index DLQI
- 36-Item Short Form Survey (SF-36)
- REDCap will calculate automatically the scores

## Dermatology Quality Index – DLQI

- Skin conditions
- Adults
- 10 questions
- Score range 0 to 30

#### DERMATOLOGY LIFE QUALITY INDEX

			DLQI
Hospital No:	Date:		
	Duton		
Name:		Score:	
Address:	Diamaria		
Address:	Diagnosis:		

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick f one box for each question

1.	Over the last week, how <b>itchy</b> , <b>sore</b> , <b>painful</b> or <b>stinging</b> has your skin been?	Very much A lot A little Not at all				
2.	Over the last week, how <b>embarrassed</b> or <b>self conscious</b> have you been because of your skin?	Very much A lot A little Not at all				
3.	Over the last week, how much has your skin interfered with you going shopping or looking after your <b>home</b> or garden?	Very much A lot A little Not at all		Not relevant 🗖		
4.	Over the last week, how much has your skin influenced the <b>clothes</b> you wear?	Very much A lot A little Not at all		Not relevant 🗖		
5.	Over the last week, how much has your skin affected any <b>social</b> or <b>leisure</b> activities?	Very much A lot A little Not at all		Not relevant 🗖		
6.	Over the last week, how much has your skin made it difficult for you to do any <b>sport</b> ?	Very much A lot A little Not at all		Not relevant 🗖		
7.	Over the last week, has your skin prevented you from <b>working</b> or <b>studying</b> ?	Yes No		Not relevant 🗖		
	If "No", over the last week how much has your skin been a problem at <b>work</b> or <b>studying</b> ?	A lot A little Not at all				
8.	Over the last week, how much has your skin created problems with your <b>partner</b> or any of your <b>close friends</b> or <b>relatives</b> ?	Very much A lot A little Not at all		Not relevant 🗖		
9.	Over the last week, how much has your skin caused any <b>sexual</b> difficulties?	Very much A lot A little Not at all		Not relevant 🗖		
10.	Over the last week, how much of a problem has the <b>treatment</b> for your skin been, for example by making your home messy, or by taking up time? Please check you have answered EVER?	Very much A lot A little Not at all		Not relevant 🗖		
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## 36-Item Short Form Survey (SF-36)

- General quality of life evaluation

   physical and mental health
- Self-reporting
- Validated in several languages
- 36 items assessing 8 health sections: vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning and mental health.
- Score range 0 to 100





RAND > RAND Health > Surveys > RAND Medical Outcomes Study > 36-Item Short Form Survey (SF-36) >

### **36-Item Short Form Survey Instrument** (SF-36)

#### **RAND 36-Item Health Survey 1.0 Questionnaire Items**

Choose one option for each questionnaire item.

1. In general, would you say your health is:

- 0 1 Excellent
- 🔘 2 Very good
- 🔵 3 Good
- 🔵 4 Fair
- 🔿 5 Poor

2. Compared to one year ago, how would you rate your health in general now?

- 🔿 1 Much better now than one year ago
- $\bigcirc$  2 Somewhat better now than one year ago
- 🔘 3 About the same
- $\bigcirc$  4 Somewhat worse now than one year ago
- 🔘 5 Much worse now than one year ago

### Summary

- PROM
- HRQoL questionnaires
- Objective measurement tools
- DLQI and SF-36
- REDCap