Presidenza del Consiglio dei Ministri

CONFERENZA PERMANENTE PER I RAPPORTI TRA LO STATO, LE REGIONI E LE PROVINCE AUTONOME DI TRENTO E DI BOLZANO

Accordo, ai sensi dell'articolo 4 del decreto legislativo 28 agosto 1997, n. 281, tra lo Stato, le Regioni e le Province autonome di Trento e Bolzano sul documento recante "Linee di indirizzo su linfedema ed altre patologie correlate al sistema linfatico".

Rep. Atti n. 159/CSR del 15 settembre 2016

LA CONFERENZA PERMANENTE PER I RAPPORTI TRA LO STATO, LE REGIONI E LE PROVINCE AUTONOME DI TRENTO E BOLZANO

Nella odierna seduta del 15 settembre 2016

VISTO il decreto legislativo 28 agosto 1997, n. 281, che all'articolo 4 affida a questa Conferenza il compito di promuovere e sancire accordi tra il Governo, le Regioni e le Province autonome in attuazione del principio di leale collaborazione, al fine di coordinare l'esercizio delle rispettive competenze e svolgere attività di interesse comune.

Sandro Michelini MD San Giovanni Battista Hospital - Rome - Italy

Marina Cestari MD O.U. Territorial Rehabilitation-NHS Umbria 2 - Terni - Italy

INTRODUCTION

With an Italian poll we decided to the ILF-COM project the aim of which is to develop an internationally agreed outcomes measures in chronic oedema useful in clinical practice and research.

AIM

We agreed to be part of this important project because its purpose is to develop an internationally agreed set standards for the outcome of treatment for chronic oedema also useful in our country.

METHODS

We carried out the survey according to ILF-COM protocol: using the link https://www.surveymonkey.com/r/CYSCKKT and using a QR code through which the survey could be accessed by mobile phone.

ACTIVITIES

Our study site was activated to carry out the survey, also using the Italian Lymphoedema Framework website for wider dissemination, and with the results of the survey worked on the design of the poster.

LOCAL STEERING GROUP

The local steering group was the Italian Lymphoedema Framework. Physicians, physiotherapists, nurses, patients and industry representatives were involved in the survey.

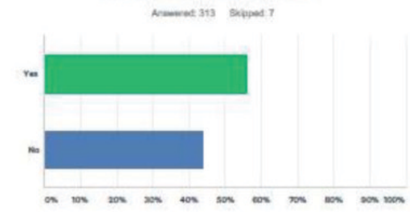
RESULTS

The elaborated data of the Italian survey showed an Italian territorial non-homogeneous in every questionnaire survey field above all in the outcome measures used, health care system and reimbursement.

Q1 Q1. Country:

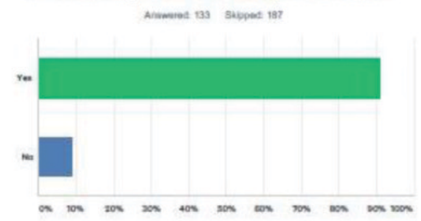
TOTAL	320

Q2 Q2. Are you a patient?



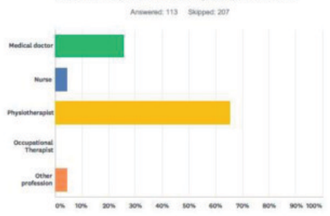
ANSWER CHOICES	RESPONSES	
Yes	56.23%	176
No	43.77%	137
TOTAL		313

Q3 Q3. Are you a healthcare professional?

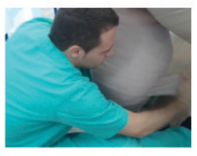


ANSWER CHOICES	RESPONSES	
Yes	90.98%	121
No	9.02%	12
TOTAL		133

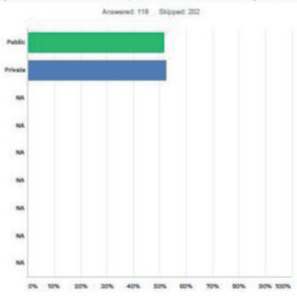
Q4 If YES please select your profession:



ANSWER CHOICES	RESPONSES	
Medical doctor	25.66%	29
Nurse	4.42%	5
Physiotherapist	65.49%	74
Occupational Therapist	0.00%	0
Other profession	4.42%	5
TOTAL		113

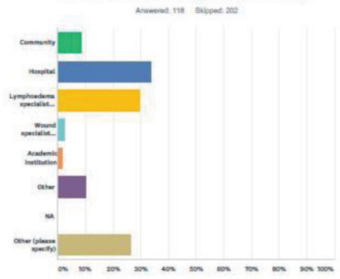


Q5 Q4. If you are a healthcare professional, what is your workplace?



ANSWER CHOICES	RESPONSES	
Public	51.69%	61
Private	52.54%	62
NA	0.00%	0
NA	0.00%	0
NA	0.00%	0
NA	0.00%	0
NA	0.00%	0
NA	0.00%	0
NA	0.00%	0
Total Respondents: 118		

Q6 Please select the type of your facility:

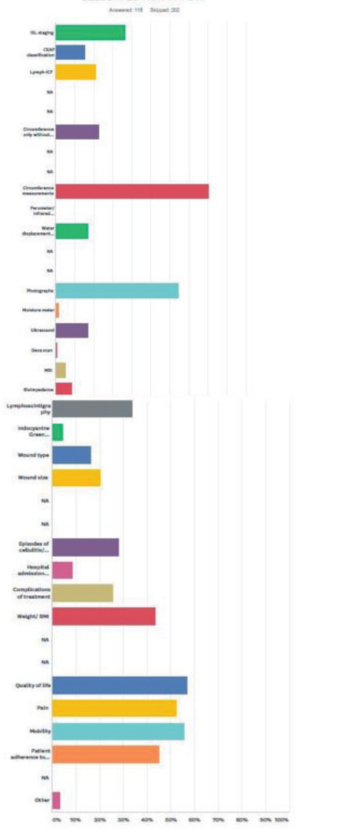


ANSWER CHOICES	RESPONSES	
Community	8.47%	10
Hospital	33.90%	40
Lymphoedema specialist centre	29.66%	35
Wound specialist centre	2.54%	3
Academic institution	1.69%	2
Other	10.17%	12
NA	0.00%	0
Other (please specify)	26.27%	31
Total Respondents: 118		

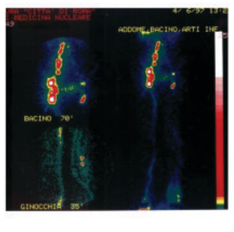
Q7 Q5. Healthcare professionals: Do you treat patients with chronic oedema/ lymphoedema?

ANSWER CHOICES	RESPONSES	
Yes	93.22%	110
No	5.93%	7
Don't know	0.85%	1
TOTAL		118

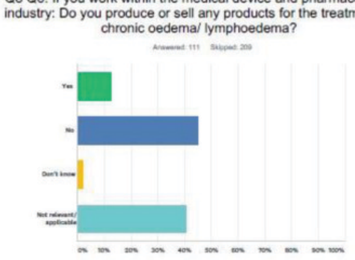
Q11 Q9. Healthcare professionals and industry: What of the following do you use in every day practice to determine outcome?PLEASE SELECT ALL THAT APPLY.



ANSWER CHOICES	RESPONSES	
ISL staging	36.44%	43
CEAP classification	15.25%	18
Lymph-ICF	21.19%	25
NA	0.00%	0
NA	0.00%	0
Circumference only without calculating volume	22.88%	27
NA	0.00%	0
Circumference measurements	80.51%	95
Perometer/ Infrared imaging	0.00%	0
Water displacement method	16.95%	20
NA	0.00%	0
NA	0.00%	0
Photographs	64.41%	76
Moisture meter	1.69%	2
Ultrasound	16.95%	20
Dexa scan	0.85%	1
MRI	5.08%	6
Bioimpedance	8.47%	10
Lymphoscintigraphy	33.90%	40
Indocyanine Green Lymphography (ICG)	4.24%	5
Wound type	16.10%	19
Wound size	20.34%	24
NA	0.00%	0
NA	0.00%	0
Episodes of cellulitis/ erysipelas	27.97%	33
Hospital admission linked to chronic oedema/ lymphoedema	8.47%	10
Complications of treatment	25.42%	30
Weight/ BMI	43.22%	51
NA	0.00%	0
NA	0.00%	0
Quality of life	56.78%	67
Pain	52.54%	62
Mobility	55.93%	66
Patient adherence to treatment	44.92%	53
NA	0.00%	0
Other	3.39%	4
Total Respondents: 118		

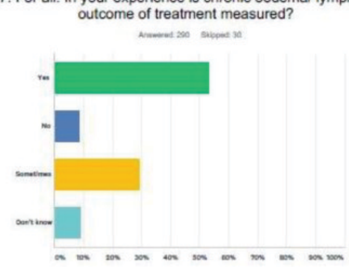


Q8 Q6. If you work within the medical device and pharmaceutical industry: Do you produce or sell any products for the treatment of chronic oedema/ lymphoedema?



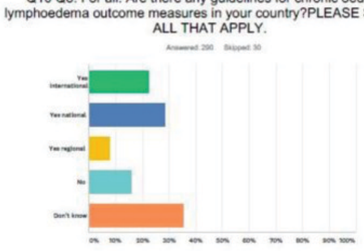
ANSWER CHOICES	RESPONSES	
Yes	12.61%	14
No	45.05%	50
Don't know	1.80%	2
Not relevant/ applicable	40.54%	45
TOTAL		111

Q9 Q7. For all: In your experience is chronic oedema/ lymphoedema outcome of treatment measured?



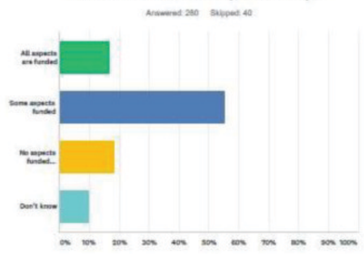
ANSWER CHOICES	RESPONSES	
Yes	53.45%	155
No	8.28%	24
Sometimes	29.31%	85
Don't know	8.97%	26
TOTAL		290

Q10 Q8. For all: Are there any guidelines for chronic oedema/ lymphoedema outcome measures in your country?PLEASE SELECT ALL THAT APPLY.



ANSWER CHOICES	RESPONSES	
Yes international	22.41%	65
Yes national	28.28%	82
Yes regional	7.59%	22
No	15.86%	46
Don't know	35.17%	102
Total Respondents: 290		

Q12 Q10: For all: What aspects of chronic oedema/ lymphoedema treatment are funded in your country?

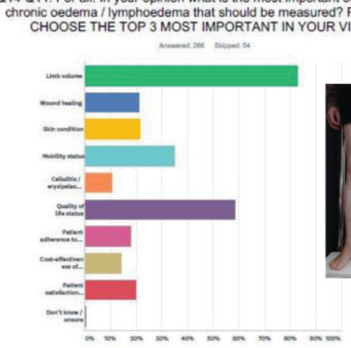


ANSWER CHOICES	RESPONSES	
All aspects are funded	16.79%	47
Some aspects funded	55.36%	155
No aspects funded (patients have to pay for everything)	18.21%	51
Don't know	9.64%	27
TOTAL		280

Q13 If SOME ASPECTS ARE FUNDED, what does the patient have to pay for:PLEASE TICK ALL THAT APPLY

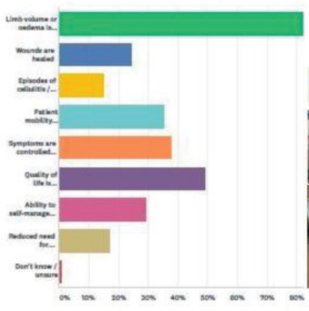
ANSWER CHOICES	RESPONSES	
Skin care advice	23.03%	35
Wound dressing	23.68%	36
Antibiotic	19.08%	29
[illegible]	[illegible]	[illegible]
Compression garment	78.29%	119
Compression bandage	67.76%	103
Compression wrap	68.42%	104
Night bandages	58.55%	89
Pneumatic compression pump	56.58%	86
Lymphoedema surgery	13.16%	20
Liposuction	27.63%	42
Exercise	34.87%	53
Kinesio taping	36.18%	55
Psychologist	34.21%	52
Other	5.26%	8
Total Respondents: 152		

Q14 Q11. For all: In your opinion what is the most important outcome in chronic oedema / lymphoedema that should be measured? PLEASE CHOOSE THE TOP 3 MOST IMPORTANT IN YOUR VIEW



ANSWER CHOICES	RESPONSES	
Limb volume	83.08%	221
Wound healing	21.05%	56
Skin condition	21.43%	57
Mobility status	34.96%	93
Cellulitis / erysipelas episodes	10.53%	28
Quality of life status	59.65%	159
Patient adherence to treatment	18.05%	48
Cost-effectiveness of treatment	14.29%	38
Patient satisfaction with treatment	19.92%	53
Don't know / unsure	0.38%	1
Total Respondents: 266		

Q15 Q12. For all: What do you believe is a successful outcome for chronic oedema / lymphoedema treatment? PLEASE CHOOSE THE TOP 3 MOST IMPORTANT IN YOUR VIEW



CLINICAL CASE

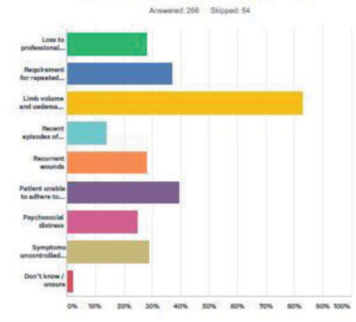
Before and after the treatment (6 weeks of hospitalization)

ANSWER CHOICES	RESPONSES	
Limb volume or oedema is stable	81.95%	218
Wounds are healed	24.44%	65
Episodes of cellulitis / erysipelas are reduced	15.04%	40
Patient mobility improved	35.34%	94
Symptoms are controlled (e.g. pain, heaviness)	37.97%	101
Quality of life is improved (e.g. emotions, sleep, social participation)	49.25%	131
Ability to self-manage with professional support	29.32%	78
Reduced need for professional treatment	16.92%	45
Don't know / unsure	0.75%	2
Total Respondents: 266		

CLINICAL CASE

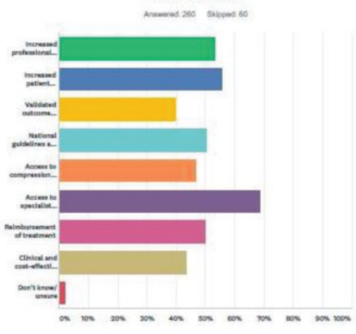
Before and after the treatment (5 days - lymphoedema specialist centre)

Q16 Q13. For all: In your view what factors do you believe indicate that treatment is ineffective or failing? PLEASE CHOOSE THE TOP 3 MOST IMPORTANT IN YOUR VIEW



ANSWER CHOICES	RESPONSES	
Loss to professional follow-up	27.82%	74
Requirement for repeated intensive treatment	36.84%	98
Limb volume and oedema increased	83.08%	221
Recent episodes of cellulitis / erysipelas	13.91%	37
Recurrent wounds	27.82%	74
Patient unable to adhere to treatment	39.47%	105
Psychosocial distress	24.81%	66
Symptoms uncontrolled (e.g. pain, heaviness)	28.95%	77
Don't know / unsure	1.88%	5
Total Respondents: 266		
Compression garment	78.29%	119
Compression bandage	67.76%	103
Compression wrap	68.42%	104
Night bandages	58.55%	89
Pneumatic compression pump	56.58%	86
Lymphoedema surgery	13.16%	20
Liposuction	27.63%	42
Exercise	34.87%	53
Kinesio taping	36.18%	55
Psychologist	34.21%	52
Other	5.26%	8
Total Respondents: 152		

Q17 Q14. For all: What factors could improve the adoption of chronic oedema/ lymphoedema outcome measures? PLEASE SELECT ALL THAT APPLY.



ANSWER CHOICES	RESPONSES	
Increased professional knowledge	53.08%	138
Increased patient knowledge	55.77%	145
Validated outcome measures	40.00%	104
National guidelines and standards	50.38%	131
Access to compression therapy	46.92%	122
Access to specialist chronic oedema/ lymphoedema services	68.85%	179
Reimbursement of treatment	50.00%	130
Clinical and cost-effective research in chronic oedema/ lymphoedema treatment	43.46%	113
Don't know/ unsure	1.92%	5
Total Respondents: 260		

CONCLUSION

With the knowledge that, in spite of our effort, the adherence to the survey was not as expected, as a national framework we are, however, satisfied to have participated in the Chronic Oedema Outcome Measures project with the awareness of the importance to set international standards.