

## MULTI-COMPOSITE TISSUE ADVISORY GROUP

### Quality of life after Intestinal Transplant

Quality of life (QoL) is an important metric to understand the impact that intestinal transplant has on patients, compared to that prior to transplant, generally on home parenteral nutrition. Disease-specific and generic metrics are both necessary to understand the impact, so that outcomes can be compared across other chronic conditions.

#### Working group

Duncan Massey and Phil Allan have agreed the routine collection of QoL in adults in 3 formats:

- EQ5D-5
- SF36
- HPN-QOL/ITx-QOL

Better disease specific metrics are needed, which will involve mixed methods and biostatistical analysis of the validity (construct/discriminant and face validity), reliability and responsiveness. This is being examined in Oxford, where Ray Fitzpatrick and Michelle Peters have specific expertise in developing patient-reported outcomes (PROMs)

#### Data collection

Timing agreed at:

- Transplant assessment (pre-transplant)
- 3 months, 6 months and 12 months post-transplant
- Then annually.

Collection strategies not standardised, but currently by mailing hard copies or giving copies to clinic attendees.

EuroQOL have agreed 1000 tests per year, including multiple tests per patient until 10/10/2020. Beyond this agreement the licence fee is a remarkable €10000 per patient. The agreement is attached.

#### Data

*Presented 2017*

		Overall Cohort					Cohort with paired pre- and post-ITx data				
		Pre		Post		p value	Pre		Post		p value
		Mean	±95%CI	Mean	±95%CI		Mean	±95%CI	Mean	±95%CI	
EQ5D	Mobility	3.33	0.56	4.48	0.30	<b>0.0003</b>	3.29	0.82	4.47	0.34	<b>0.0049</b>
	Self-care	4.00	0.57	4.58	0.28	0.0519	3.57	0.94	4.71	0.28	<b>0.0061</b>
	Usual activity	2.33	0.49	3.81	0.33	<b>0.0000</b>	2.14	0.67	3.82	0.35	<b>0.0001</b>
	Pain/discomfort	2.33	0.68	3.74	0.36	<b>0.0003</b>	2.14	0.90	4.18	0.25	<b>0.0000</b>
	Anxiety/Depression	4.00	0.51	4.52	0.27	0.0598	4.00	0.86	4.53	0.38	0.2088
	VAS	35.29	12.19	69.25	7.48	<b>0.0000</b>	40.71	21.32	73.47	6.94	<b>0.0011</b>
SF36	Physical Functioning	43.45	8.65	63.27	10.50	<b>0.004</b>	39.94	22.56	66.08	10.64	<b>0.0287</b>
	Role limitations due to physical health	25.13	7.76	50.94	10.59	<b>0.001</b>	16.67	23.10	40.00	19.01	0.1466
	Role limitations due to emotional problems	32.85	10.72	61.83	11.38	<b>0.001</b>	59.26	32.26	77.78	17.65	0.2929
	Energy/Fatigue	15.15	10.62	37.07	16.01	<b>0.047</b>	27.78	14.50	44.69	12.65	0.1128
	Emotional well-being	56.35	18.65	68.75	16.42	0.187	55.56	13.79	68.19	11.41	0.1921
	Social Functioning	22.73	8.22	47.79	11.00	<b>0.002</b>	33.33	21.61	64.84	13.08	<b>0.0160</b>
	Pain	58.95	8.74	68.15	9.65	0.076	36.67	21.85	68.91	11.43	<b>0.0093</b>
General Health	37.50	11.95	61.67	13.36	<b>0.007</b>	23.33	16.50	42.81	9.96	<b>0.0460</b>	

*Since Oct 2017 (last MCTAG)*

Oxford: 6 further data sets

Cambridge: 5 further data sets

Further data insufficient for meaningful statistical analysis at this stage.

**Phil Allan**

**Dunecan Massey**