WP4: HTA and QoL Measurement Online surveys

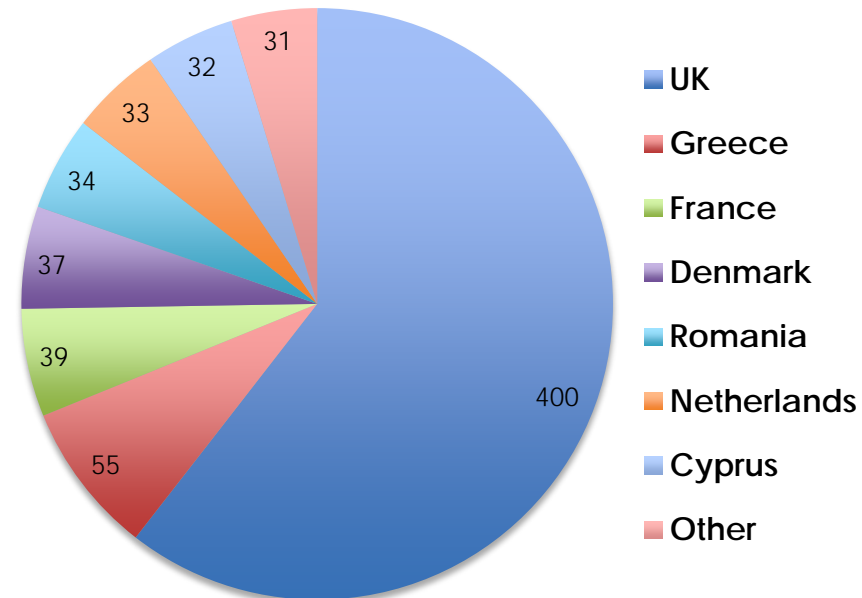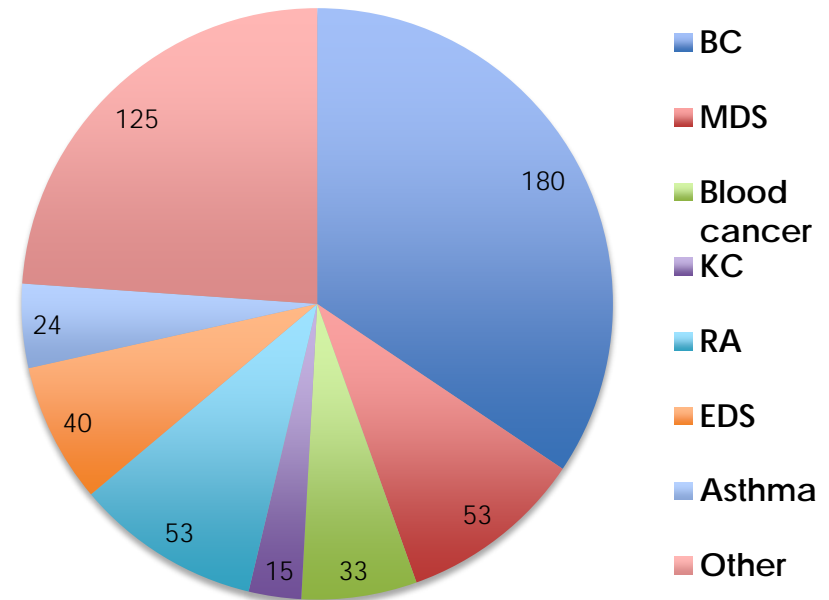Olina Efthymiadou   Panos Kanavos   Jean Mossman

Methods – Questionnaire design

1. Demographics: age; country of residence; marital, education and employment status; relationship to the patient

2. Clinical characteristics; disease area; years since diagnosis/provision of care; satisfaction with treatment received

3. EQ-5D-5L Health state utility (EQ-5D-5L), self-perceived health (EQ-5D-5L   VAS)

4. Views about important QoL aspects not captured by EQ-5D-5L

5. Additional QoL dimensions: patients' disability (Barthel Index) and caregivers' emotional burden (Zarit Burden Interview)

Methods – Email Invitations

- 293 patient organisations
- 47 countries invited (EU & Intl')

Results – Responses

Legend:
- BC
- MDS
- Blood cancer
- KC
- RA
- EDS
- Asthma
- Other

Values: 180, 125, 24, 40, 53, 15, 33, 53

Legend:
- UK
- Greece
- France
- Denmark
- Romania
- Netherlands
- Cyprus
- Other

Values: 400, 55, 39, 37, 34, 33, 32, 31

Results –   Patient characteristics & QoL

Table 1. Patient employment and demographics (n=767)	
Age (mean, SD)	**50 (14.13)**
Age at diagnosis (mean ,SD)	39 (17.5)
Gender, Female (n,%)	**591 (77%)**
Marital status (n,%)	
Single	174 (23%)
Married or cohabiting	513 (67%)
Divorced	50 (7%)
Separated	15 (2%)
Widow	15 (2%)
Employment status (n,%)	
Employed	**312 (40.7%)**
Unemployed	27 (3.5%)
Temporary sick leave	58 (7.5%)
Permanent work disability	19 (2.5%)
Retired	83 (10.9%)
Housewife/husband	**182 (23.8%)**
Student	30 (3.9%)

Table 3. All patient QoL and Disability Mean (SD) or n (%)	
EQ5D Utility	0.62 (0.27)
Utility loss	0.24 (0.27)
EQ5D VAS	63 (23.35)
Barthel index	18.2 (3.25)
Independent (20)	175 (54%)
Mildly dependent (15-19)	119 (37%)
Moderately dependent (10-14)	19 (6%)
	12 (4%)
Severely dependent (0-9)	

Results – Caregiver characteristics & QoL

Table 2. Caregiver employment and demographics (n=77)	
Age (mean, SD)	**54 (11.8)**
Gender: Female (n,%)	**61 (79%)**
Relationship to the patient (n,%)	
Spouse	**44 (57%)**
Son/Daughter	10 (13%)
Parent	19 (25%)
Son/Daughter in law	0%
Sibling	2 (3%)
Employment status (n,%) Employed	
Retired	34 (44%)
Housewife/husband	26 (34%)
Work limitation (last 12 months) - If employed (n=34)	**17 (50%)**
Early retirement – If retired (n=26)	5 (6.5%)

Table 4. All caregiver QoL & emotional burden (n=77) Mean (SD) or n (%)	
EQ5D Utility	0.72 (0.23)
EQ5D Utility	0.15 (0.23)
EQ5D VAS	69 (20.7)
Zarit burden score	35 (9.4)
<46—no burden	71 (91%)
46 – 54—mild burden	7 (8%)
>54—severe burden	0%

Results –Disease specific characteristics & QoL

Table 5: Characteristics and HRQOL results of patients and caregivers across sample main disease areas (Average figures)							
	All sample	BC	RA	MDS	EDS	Blood cancer	Asthma
Patient age	50	53	47	65	35	57	49
Caregiver sample	77	5	2	11	3	7	2
Caregiver age	54	57	54	63	44	55	45
Patient Satisfaction	6.5	7.7	6.4	8.1	4.6	8.2	7.0
Caregiver Satisfaction	6.4	6.8	3.0	7.7	5.0	7.4	6.0
Patient Utility	0.62	0.70	0.60	0.70	0.33	0.50	0.74
Patient Utility loss	24%	15.2%	**27.6%**	16%	**53.1%**	**35.2%**	12.3%
Caregiver Utility	0.72	0.73	0.81	0.73	0.76	0.88	0.44
Caregiver utility loss	14%	14%	6%	12.7%	10.2%	0%	42%
VAS patients	63	69	67	67	45	53	63
VAS caregivers	69	81	85	79	68	71	61
Barthel index	18.34	19.59	18.06	18.84	15.29	16.93	18.83
Zarit scale	35	27	32	32	36	29	34

Results – Country specific characteristics & QoL

Table 6: Characteristics and HRQOL results of patients and caregivers across countries (Average figures)							
	All sample	UK	Greece	France	Denmark	Romania	Netherlands	Cyprus
Patient age	50	52	44	56	49	40	55	48
Caregiver sample	77	39	3	–	6	2	1	1
Caregiver age	54	57	54	–	57	55	45	30
Patient Satisfaction	6.5	6.8	6.0	6.0	7.9	5.6	6.9	5.5
Caregiver Satisfaction	6.4	6.8	5.3	–	6.7	1.0	6.0	2.0
Utility patients	0.62	0.60	0.58	0.53	0.78	0.69	0.61	0.63
Utility caregivers	0.72	0.68	0.79	–	0.87	0.85	0.84	0.72
Benchmark population utility	–	0.86	0.86	0.83	0.85	0.86	0.87	0.86
VAS patients	63	61	61	62	69	66	62	67
VAS caregivers	69	70	71	–	75	60	95	80
Barthel index	18.34	18.47	18.29	18.9	18.9	17.9	17.2	18.7
Zarit scale	35	34.8	37.3	–	27	31.5	26	26

Results - Patient Evaluation of EQ-5D-5L tool

"Are there any aspects of your illness, which have had a big impact on your health, that were not captured by the EQ-5D-5L?"
- Yes (n=359, **51%**)
- *Please tell us what they are* (n=325, **46%**)

	Fatigue	Side Effects	Cognitive problems	Relationships /social life	Family issues	Co-Morbidities	Sleep	Fear for future	Work issues	Financial issues
All sample (n=325)	19.5%	9%	6.5%	6.2%	5.3%	5%	4.6%	3.5%	3%	2.2%
BC (n=83)	21.7%	20.5%	9.5%	3.6%	4.8%	1.2%	2.4%	3.6%	1.2%	2.4%
MDS (n=30)	40%	13.3%	3.3%	-	3.3%	-	3.3%	6.6%	3.3%	-
Blood cancer (n=11)	9%	18%	9%	9%	18%	9%	-	18%	9%	-
KC (n=8)	37.5%	12.5%	-	-	12.5%	-	-	-	-	-
RA (n=20)	15%	5%	-	5%	-	-	5%	-	5%	-
AS (n=6)	33%	-	33%	33%	-	-	-	-	16.6%	-
PsA (n=4)	25%	-	-	-	-	25%	-	-	50%	-
EDS (n=27)	30%	-	15%	11%	7.5%	7.5%	3.7%	-	7.5%	3.7%
Asthma (n=15)	-	-	-	7%	7%	-	7%	-	7%	-
ET (n=9)	11%	-	-	22%	11%	11%	-	-	-	11%
RLS (n=13)	7.7%	7.7%	7.7%	-	-	-	70%	-	-	-
HMS (n=6)	83.3%	-	16.6%	-	-	16.6%	-	-	-	-
HIV (n=3)	-	66.6%	-	33.3%	-	-	-	-	-	-

Other domains not captured:

- Sexual problems (1.9%)
- Loss of confidence/self-esteem (1.9%)
- Inability to exercise (1.5%)
- Emotional distress (1.2%)
- Inability to travel (<1%)
- Loss of senses; eyesight and hearing (<1%)

Other comments:

- Tool is too general (2.2%) - *"It barely scratches the surface"*

- Doesn't capture daily variations (1.5%) - *"My health can change rapidly even by the minute. I can have a good and a bad day"*

- Specific aspects of existing EQ-5D-5L domains(8%):
    - Anxiety/depression(4%); *"Anxiety for relapse"*

    - Pain (3%); *"Control of chronic joint pain"*

    - Mobility (1%); *"Losing mobility"*

Main findings & Recommendations

Patient QoL

- 24% utility loss
- Poor HRQoL outcomes due to "Pain/discomfort" and difficulties in carrying out "Usual activities"
  - ❖ Need for greater availability of pain & fatigue management services
  - ❖ Role of fatigue in ADLs

Caregiving burden

- 15%utility loss
- ~6.5 hours of caregiving daily
- $\Rightarrow$ 50% productivity losses
- ❖ Important aspect not captured by EQ-5D-5L; Inefficiency/unavailability of social services - impact on stress levels and personal time
- ❖ Need larger sample for accurate conclusions

EQ-5D-5L limitations

- "Important" aspects are not captured for patients (51%) and caregivers (40%)
  - ❖ Further research needed in this area
  - ❖ Better methodology needed to ensure what matters to patients is captured in cost effectiveness assessments using generic tools