

Health related quality of life aspects not captured by EQ-5D-5L: Results from an international survey of patients

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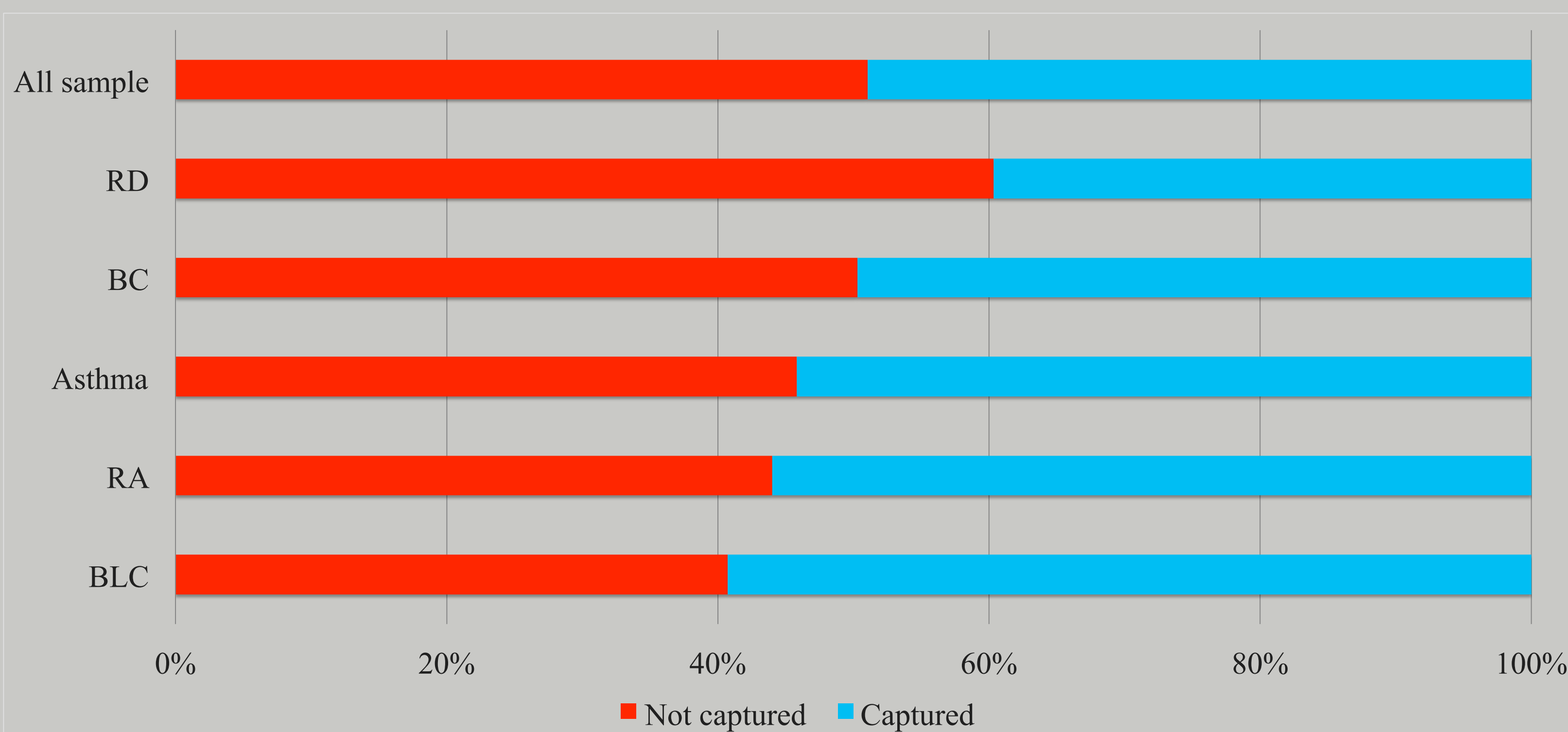
2. European Brain Council

Background & Objectives

By imposing pre-defined domains on HRQoL measurement EQ-5D-5L is believed to lack dimensions of HRQL that may be impacted by chronic diseases such as dexterity, social functioning and vitality and therefore, raises questions on the extent to which it represents the pragmatic QoL of individual patients or groups of patients [1-3] which is shaped by a unique combination of different important aspects for each individual.

- ❖ In view of the widespread role of EQ-5D-5L in reimbursement decisions, we aimed to ascertain the perspective of individuals suffering from a variety of chronic conditions on how well the EQ-5D-5L reflected their experience of illness.

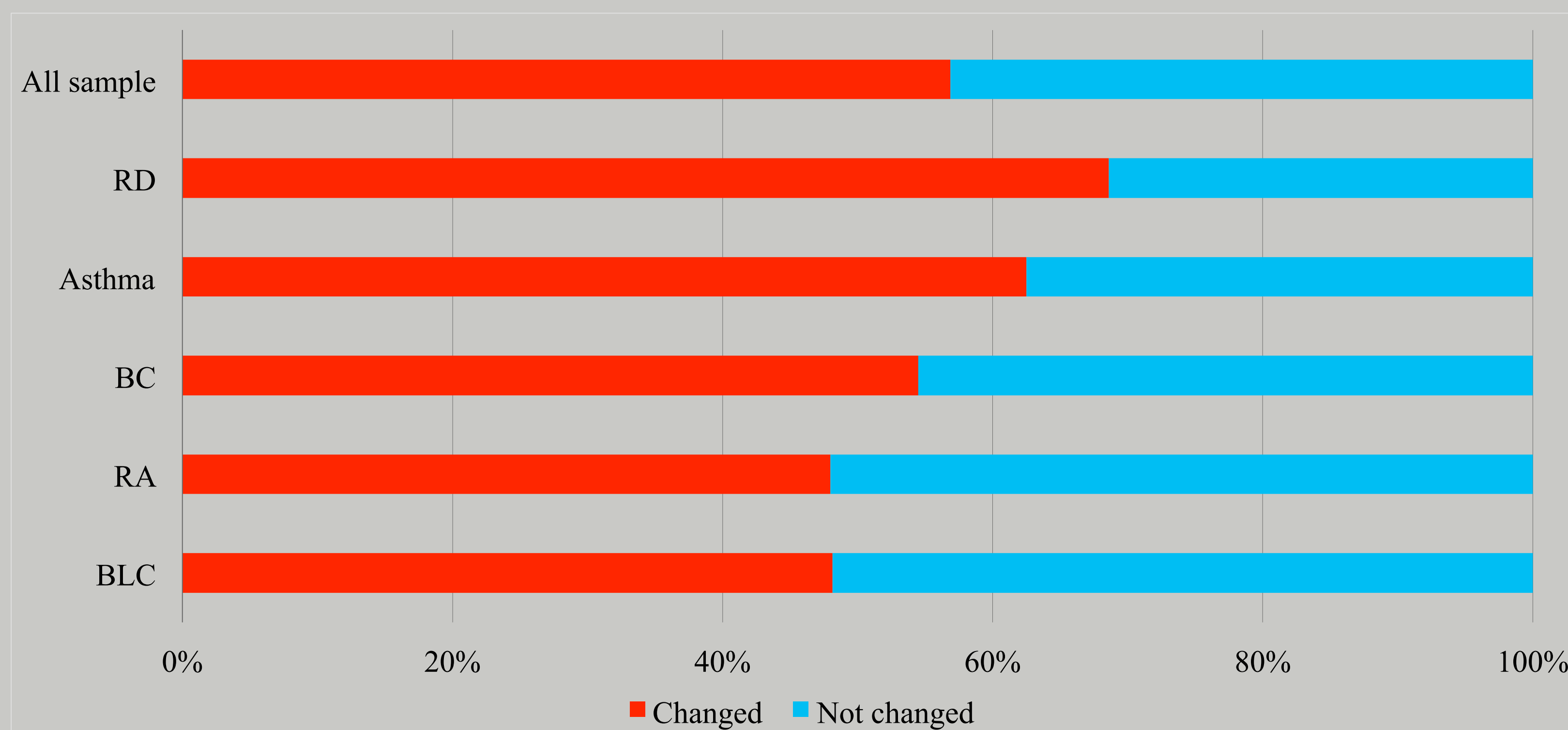
Figure 1. Proportion of patients across all sample and main disease areas reporting aspects not captured by the EQ-5D-5L



Methods

- A web-survey (Qualtrics ®) of individuals with a chronic condition, mainly breast cancer (BC), blood cancers (BLC), rheumatoid arthritis (RA), asthma, and rare diseases (RD).
- Patient organisations across 47 countries were invited to voluntarily share the survey tool with their membership network.
- Survey collected data on i) Demographics, ii) QoL (EuroQoL 5-domain; EQ-5D-5L) and EQ-5D-5L VAS, iv) Other, non EQ-5D domains which impacted greatly on their wellbeing and respondents thought were not captured by the EQ-5D and v) aspects that changed over the course of their illness
- Microsoft® Excel 2010 was used to generate descriptive statistics

Figure 2. Proportion of patients across all sample and main disease areas reporting that important QoL aspects changed over the course of their illness



Results

- 767 responses across 122 patient diagnoses* and 38 countries**
- Average patient HSUV was 0.62 (±0.27), translating to an average health state utility loss of 28% when compared to the HSUVs identified for the general population in the study countries.

❖ Important wellbeing aspects not captured by EQ-5D-5L

• Evaluation of the EQ-5D-5L tool showed that 51% (n=359) of all patients who responded (n=705) on the question; “which aspects of their illness had a big impact on their health, that were not captured by the EQ-5D-5L”, consider this instrument insufficient in capturing all of the important wellbeing aspects that added a significant burden to their HRQoL and this percentage fluctuated between disease groups, amounting up to 60% for RD, 45% for BC and just above 40% for Asthma, RA and BLC patients (Figure 1)

• Such aspects mainly included **fatigue (19% of respondents)**, medication side effects (12%) and maintenance of social life (6.5%) (Table 1). Less commonly reported aspects included sleep deprivation (4.3%), loss of confidence/self-esteem (1.9%) (i.e. “*Self-image, confidence*”, “*The view I have of myself*”), sexual dysfunction (1.8%) (i.e. “*Sexual discomfort*”, “*Vulvar fragility*”), inability to exercise (1.5%), emotional distress (1.2%), inability to travel (<1%) and loss of senses; eyesight and hearing (<1%).

❖ Important wellbeing aspects that changed over the course of patients' illness

• 57% (n=401) of all patients who responded (n=705) consider that the aspects of their illness that have a big impact on their health have changed over the course of their disease and this percentage fluctuated between disease groups (Figure 2).

• **Fatigue** and **Pain/Discomfort** were the most commonly reported (17% and 14% of respondents respectively) QoL aspects that changed over the course of patients' illness, followed by mobility (12.4%) and SEs (11.4%) (Table 2).

• Other less commonly reported aspects that changed included fear for relapse/ for future; (2.4%), sleep deprivation (2.1%), sexual dysfunction (1.3%), financial problems (1%), loss of confidence/self-esteem (1%), maintenance of family relationships (1%), appearance/ bodily image (<1%), loss of senses; eyesight and hearing (<1%), and self-care (<1%).

*Mainly BC (n=180, 23.5% of study sample), BLC (n=31, 4%), RD (n=140, 18.2%), RA (n=53, 6.9%) and Asthma (n=24, 3.1%)

**Mainly UK (52%), Greece (7%), France (5%), Denmark (5%), Romania (4.5%), the Netherlands (4%), Cyprus (4%), Croatia (2%), Slovenia (2%), Germany (1%) and Spain (1%).

Table 1. QoL aspects which according to the respondents were not captured by the EQ-5D-5L

	Fatigue	SEs	Co-Morbidities	Relationships/ social life	Medical social care received	Cognitive impairment	Sleep deprivation	Family relationships	Fear for future	Work limitation	Financial issues
All sample (n=325)	19% (n=62)	12% (n=39)	9.5% (n=31)	6.5% (n=21)	6.2% (n=20)	4.3% (n=14)	4.3% (n=14)	3.7% (n=12)	3.7% (n=12)	3.7% (n=12)	2% (n=7)
BC (n=83)	22% (n=18)	19% (n=16)	2.4% (n=2)	4.8% (n=4)	8.4% (n=7)	8.4% (n=7)	1.2% (n=1)	2.4% (n=2)	4.8% (n=4)	1.2% (n=1)	2.4% (n=2)
BLC (n=11)	9.1% (n=1)	18.2% (n=2)	18.2% (n=2)	9.1% (n=1)	-	9.1% (n=1)	-	18.2% (n=2)	18.2% (n=2)	-	-
RA (n=14)	28.6% (n=4)	14.3% (n=2)	7.1% (n=1)	7.1% (n=1)	7.1% (n=1)	-	7.1% (n=1)	-	-	7.1% (n=1)	-
RD (n=66)	19.7% (n=13)	3% (n=2)	12.1% (n=8)	15.1% (n=10)	6% (n=4)	4.5% (n=3)	1.5% (n=1)	4.5% (n=3)	-	5% (n=3)	4.5% (n=3)
Asthma (n=11)	-	9.1% (n=1)	-	9.1% (n=1)	-	-	9.1% (n=1)	9.1% (n=1)	-	9.1% (n=1)	-

Table 2. Most common aspects of patients' illness that had a big impact on their health and that changed over the course of their disease

	Changes on EQ-5D-5L aspects				Changes on aspects not included in the EQ-5D-5L						
	Mobility	Usual Activities	Pain/Discomfort	Anxiety/Depression	Fatigue	SEs	Treatment received	Work limitation	Relationships/ Social life	Co-morbidities	Cognitive impairment
All sample (n=370)	12.4% (n=46)	4.3% (n=16)	14% (n=5)	2.7% (n=10)	17% (n=63)	11.4% (n=42)	7% (n=26)	6.5% (n=24)	3.8% (n=14)	3% (n=11)	2.7% (n=10)
BC (n=86)	3.5% (n=3)	7% (n=6)	24.4% (n=21)	12.8% (n=11)	18.6% (n=16)	23.2% (n=20)	4.6% (n=4)	5.8% (n=5)	1.2% (n=1)	2.3% (n=2)	1.2% (n=1)
BLC (n=13)	23% (n=3)	-	15.4% (n=2)	15.4% (n=2)	23% (n=3)	7.7% (n=1)	7.7% (n=1)	15.4% (n=2)	7.7% (n=1)	15.4% (n=2)	7.7% (n=1)
RA (n=19)	21% (n=4)	-	5.2% (n=1)	10.5% (n=2)	10.5% (n=2)	-	-	5.2% (n=1)	5.2% (n=1)	5.2% (n=1)	-
RD (n=79)	18.9% (n=15)	3.8% (n=3)	10.1% (n=8)	-	10.1% (n=8)	2.5% (n=2)	6.3% (n=5)	8.8% (n=7)	6.3% (n=5)	8.8% (n=7)	3.8% (n=3)
Asthma (n=15)	13.3% (n=2)	6.6% (n=1)	-	13.3% (n=2)	13.3% (n=2)	20% (n=3)	-	6.6% (n=1)	-	6.6% (n=1)	-

Conclusions & Future directions

We demonstrated that utilisation of the EQ-5D-5L in HRQoL measurement raises inconsistencies in capturing QoL attributes in disease-specific patient populations. However, as our study has limitations (i.e. the use of a web-survey resulted in data unable to be verified by the author and raised issues related to the patients' understanding of the EQ-5D domains and their severity levels) our results should be interpreted with caution.

- ❖ Further research is needed to clarify the extent to which other generic HRQoL measurement tools capture the aspects of health that really matter for patients.

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